HIV Prevention Study

Report to the Secretary
Washington State
Department of Health

HIV Prevention Study Committee
March 20, 2002

Produced for the HIV Prevention Study Committee, 2002, under the direction of the Washington State Department of Health, Office of Infectious Disease and Reproductive Health:

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Executive Summary

Study Mandate

The 2001 Legislature considered Senate Bill 5679, "An Act relating to the HIV/AIDS prevention study committee." The bill recognized that the AIDS Omnibus Act of 1988 created a network of HIV/AIDS prevention efforts and programs in Washington State, but that the HIV/AIDS epidemic had changed in the intervening years. To ensure that management and distribution of funds and resources across the state are sufficiently effective to maintain current services and meet rising demands and need, the bill established an HIV/AIDS prevention study committee whose charge was to:

- Review the goals of prevention strategies under the AIDS Omnibus Act in relation to trends in the current epidemic.
- Analyze funding streams and levels for the AIDS Omnibus Act and other HIV/AIDS prevention funding.
- Review the interaction and coordination of HIV/AIDS prevention programs with care services.

The bill did not pass the Legislature. But because need remained for the review and deliberation it outlined, the Department of Health decided to carry forward the intent of the legislation. The Department established the HIV Prevention Study Committee in late-summer 2001, comprising 13 members (listed in Appendix A to the full report) with representation as outlined in the original legislation:

- The State Health Officer (Chair)
- Two senators, one from each party (or their designee)
- Two representatives, one from each party (or their designee)
- Three representatives of local public health agencies
- One representative from the State Board of Health
- Three representatives of community-based organizations
- One consumer representative living with HIV/AIDS

The committee was charged with responding to the three tasks outlined in the proposed legislation and reporting its findings and recommendations to the Secretary of the Department of Health in early 2002. This is the committee's report to the Secretary.

Study Approach

The Department of Health, Office of Infectious Disease and Reproductive Health, managed and staffed the HIV Prevention Study Committee. The Department contracted with the University of Washington Health Policy Analysis Program to assist in facilitating the

committee's work and analyzing information and data, and to prepare the Committee's report to the Secretary.

The HIV Prevention Study Committee met a total of ten times between August 2001 and February 2002. Six of the meetings were held in each of the six AIDSNet regions established by the 1988 AIDS Omnibus Act. At each of these meetings the committee heard presentations by the Department, regional AIDSNet representatives, representatives of regional HIV/AIDS prevention services planners, and public testimony. All committee meetings were open to the public and met the requirements of the Americans with Disabilities Act.

Members of the committee also participated in a statewide HIV Policy Summit held in November 2001. They presented the committee's preliminary findings to summit participants and garnered their ideas and suggestions for further consideration.

Contextual Findings

The 1988 AIDS Omnibus Act Created a Flexible Program for HIV/ AIDS Service Planning and Delivery

One of the greatest strengths of the 1988 AIDS Omnibus Act's is its creation of a flexible mechanism for developing, funding, and providing prevention services. The Act created six regional AIDS service networks, or AIDSNets, which are responsible for planning services, identifying populations for whom services will be provided, and contracting for service provision (Figure ES-1). This regional structure gives local communities a voice and role in planning, targeting, and providing services to specific populations and needs, and has created an environment for effective and supportive collaboration among public health agencies and community-based service organizations.

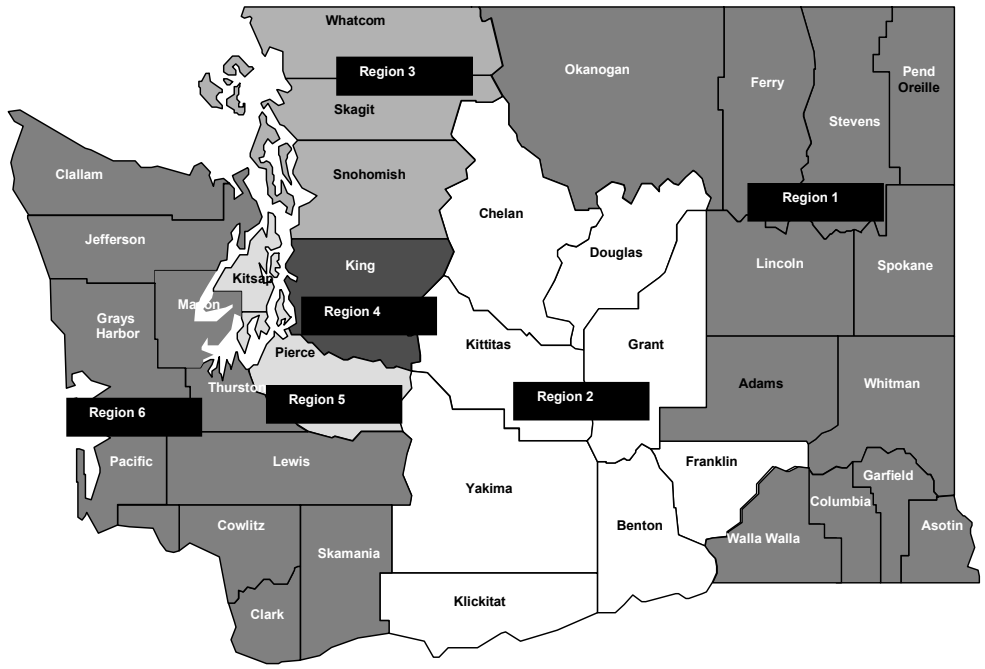
AIDS Omnibus Act Funding is Flexible, but Declining

The AIDS Omnibus Act created a flexible funding mechanism that directs funds through the Department of Health to each of the AIDSNets to support their work in planning, designing, and providing prevention services. But AIDS Omnibus dollars allocated by the Legislature have remained flat at $8.1 million since 1991, with no adjustment for inflation. Consequently, in real dollars Omnibus Act funding has decreased by approximately 21% since 1990. This decline coincides with an increase in need for prevention services, particularly among people living with AIDS, whose numbers have increased four-fold since 1991. Fewer and fewer dollars are being spread over increasing numbers of people. This has resulted in HIV/AIDS planners and providers now reducing the services they offer and the populations they serve.

The AIDS Omnibus Act Supports Coordination of Prevention and Care Services

The AIDS Omnibus Act requires that the state provide both prevention and coordination-of-

Figure ES-1: Washington State's Six Regional AIDSNets



Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

care services, but it is heavily weighted toward prevention. Successfully coordinating HIV/AIDS prevention and care services has become increasingly necessary as the epidemic has shifted from acute to chronic care. It also has become increasingly complex, largely due to federal funding requirements regarding coordination and accountability. Through their collaborative work on providing AIDS Omnibus Act prevention services, the regional AIDSNets, local and state public health agencies, and community organizations have developed a shared sense of responsibility for addressing both prevention and care, and have shown a commitment to working together on coordination strategies.

The HIV/AIDS Epidemic Has Changed Since the Act Was Passed

A Growing Number of People in Washington State are Living with HIV/AIDS

The AIDS Omnibus Act did not, and could not, foresee changes in the HIV/AIDS epidemic that have occurred over the past ten years, including medical advances that have greatly improved the prognosis for people with HIV/AIDS. Both the number of people diagnosed with AIDS and the number of AIDS deaths have decreased since the mid-1990s. In turn, the number of people living with AIDS (that is, the prevalence of AIDS) has risen steadily, reaching 4,059 people by the end of 2000 (Figure ES-2). Advances in medical care have thus created a larger population of people for whom prevention services are important.

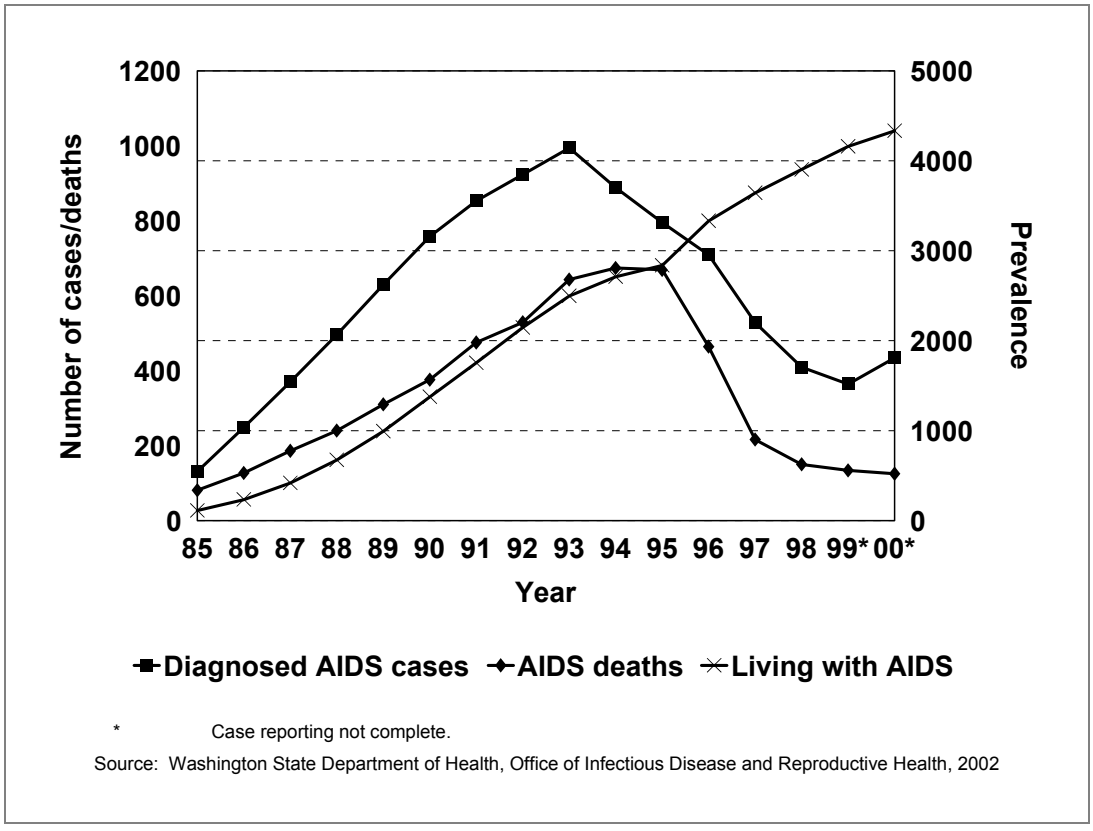
The HIV/AIDS Epidemic Has Shifted to Include Other Populations

Although white, gay men continue to comprise the largest proportion of HIV/AIDS cases in Washington State, this proportion has been declining over time. Other populations, including women and people of color, have been making up increasing proportions of those with HIV/AIDS. In addition, the proportions of cases resulting from heterosexual contact and injection drug use also have been increasing.

The Impact of the HIV/AIDS Epidemic Varies Across the State

Since 1988, when the AIDS Omnibus Act was passed, Seattle-King County has consistently had the largest proportion of AIDS cases in the state. Over time, however, this proportion has decreased – from 71% in 1988 to 57% in 1998-2000 – as the number of AIDS cases diagnosed in other areas of the state has gone up. Statewide HIV reporting, implemented in late 1999, offers insight into the geographic location of those living with HIV infection that has not progressed to AIDS. These people are closer to the front end – or leading edge – of the epidemic. Data reveal that in 1998-2000 the majority of people diagnosed with HIV in Washington state – 69% – had a King County residence at the time of diagnosis.

Figure ES-2: AIDS Incidence, Deaths, and Prevalence by Year of Diagnosis, Washington State, 1985-2000



* Case reporting not complete.

Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

Recommendations and Supporting Findings

The HIV Prevention Study Committee offers 17 recommendations to the Secretary regarding the appropriateness and effectiveness of the 1988 AIDS Omnibus Act for the epidemic as it appears today, in early 2002. The recommendations are supported by the Committee's research findings, and the Committee is unanimous in both the findings and the recommendations. The recommendations are grouped into five categories.

Recommendations 1-3: Regional AIDSNet Structure

Recommendation 1	The State should retain the regionalized approach created by the AIDS Omnibus Act to planning HIV/AIDS prevention services.
Recommendation 2	The Secretary should have authority to designate no less than five, and no more than ten, AIDSNets regions. In designating the regions, the Secretary should consider, at a minimum: ● Existing preventive service partnerships ● Patterns of travel and care ● Regional epidemiology
Recommendation 3	The State should retain the regional flexibility provided by the AIDS Omnibus Act for implementing HIV/AIDS prevention efforts.

The Committee finds that:

- The overall flexibility provided by the AIDS Omnibus Act has worked well for those implementing it. The regional AIDSNet structure facilitates identifying prevention service needs at the local level and ensures that services are provided throughout Washington State. The regional system has benefited small communities and rural regions, and has allowed for maximizing resources and sharing data and information.

- As directed by the Act, the boundaries of the six AIDSNet regions are based on the Department of Social and Health Services Community Services Administration regions as delineated in 1988. This has complicated coordinating efforts in some ways, particularly in Regions 5 and 6.

Recommendations 4-8: Funding and Accountability

Recommendation 4	The Legislature should strive to restore AIDS Omnibus Act funding to the equivalent of 1991 levels but at a minimum, maintain current funding for HIV/AIDS prevention.

Recommendation 5	The Department should retain the AIDS Omnibus Act's emphasis on using resources for HIV/AIDS prevention.
Recommendation 6	The Department should revise the current AIDSNet funding allocation formula, developed in 1995. Factors that should be used to revise the formula include, at a minimum: ● HIV reporting data ● Increased incidence and prevalence of HIV/AIDS in racial/ethnic communities
Recommendation 7	A) The regional AIDSNets should provide annual, comprehensive fiscal and activity reports to the Department and the community. The reports should be consistent across all regions. At a minimum, they should include: ● A breakdown of AIDS Omnibus Act funding by the type of service and population targeted. ● A listing of each service provider contract with the dollar amount and time frame of the contract. ● A disclosure of the amount of AIDS Omnibus Act funds being retained by each service provider for overhead and/or indirect costs. ● A breakdown of administrative costs for the AIDSNet administrative agency. ● A listing of funding received through Titles I and II of the Ryan White CARE Act, the services it was allocated to, the providers to whom it was allocated, and the amount per provider. (These reports would not include funding that agencies received independently through Titles III and IV of the Ryan White CARE Act or directly from the CDC within the AIDSNet region.) B) The Department should analyze and evaluate data from the regional AIDSNets on administrative, overhead, and indirect costs and provide feedback to stakeholders and interested state agencies comparing administrative, overhead, and indirect charges across the regional AIDSNets.
Recommendation 8	The Secretary should direct regional AIDSNets to implement programs for specific at-risk populations in communities that are unable to target these populations.

The Committee finds that:

- AIDS Omnibus Act funding and the funding allocation scheme have worked well, for the most part, over the past 12 years. But adjusting for inflation reveals that Omnibus

Act funding has decreased by approximately 21% since 1990. At the same time, the need for prevention services has risen. Fewer and fewer dollars now must be spread over a greater number of people, and AIDS Omnibus Act funding has become insufficient to meet the need for prevention services. Any reduction in AIDS Omnibus Act funds also could reduce federal Medicaid matching funds for AIDS case management.

- Since passage of the Act, the federal government has substantially increased its support of HIV/AIDS clinical care and has somewhat increased its support for prevention services, though federal support for both comes with some restrictions. The Act functions in concert with two other federal planning processes that have, over time, created more complex and demanding HIV/AIDS services planning. Developing multiple state and federal plans, each with a different fiscal year, is an administrative burden for the AIDSNets and the Department of Health.

- The current formula for allocating funds among the six AIDSNet regions does not adequately reflect the changed demographics of the epidemic, population shifts among regions, the greater difficulty in targeting rural at-risk populations, or the larger number of cases and likelihood of transmission in urban areas. Washington State has now instituted HIV reporting, in addition to AIDS reporting, which will provide more timely and accurate data about changes in the epidemic.

- The relationship between DOH and the AIDSNets is generally quite strong. Reporting standards, however, especially regarding the use of funds, should be improved.

Recommendations 9-10: Education Activities

Recommendation 9	The Secretary should work with the Superintendent of Public Instruction to develop a method of accountability, to include outcome measures, that will ensure the consistent provision and quality of HIV/AIDS education across public schools.
Recommendation 10	The Department should promote consistent, regular, risk-targeted education and training in the criminal justice system.

The Committee finds that:

- The education mandate in the AIDS Omnibus Act provides sufficient direction and guidance for implementing HIV/AIDS educational programs throughout Washington, but the Act lacks an assurance mechanism. The Act also includes many more specific requirements about general education than about risk-targeted education.

Recommendations 11-12: Coordination of Care, Prevention, and Other Related Services

Recommendation 11	The Department and the regional AIDSNets should seek out and develop more mechanisms for interaction and collaboration between care and prevention services.
Recommendation 12	The Department, other appropriate state agencies, regional and local policy makers, prevention services providers, and activists should seek out and develop mechanisms to appropriately address co-morbid factors – such as homelessness, intravenous drug use, mental illness, and poverty – to maximize the efficacy of limited HIV prevention resources to address these factors.

The Committee finds that:

- Interaction and coordination among HIV/AIDS prevention and care services is increasing as a result of identified needs, especially where clients face multiple problems such as homelessness, mental illness, substance abuse, and incarceration. But financial and system barriers to coordinating such services remain.

- The overall complement of staff within care agencies is less likely to mirror the client population demographically than are the staff in prevention agencies. This makes coordinating prevention and care more difficult and can act as a barrier to people receiving services.

Recommendations 13-17: AIDS Omnibus Act Policy Support and Changes

Recommendation 13	The Secretary should continue to support the Ellensburg Document and ensure that its principles remain in effect as an appropriate and successful mechanism for targeting funding and services to at-risk populations.
Recommendation 14	Because HIV/AIDS stigma still exists, the Secretary should strongly support the privacy and confidentiality elements of the AIDS Omnibus Act, and should sponsor and support efforts to reduce stigma. Efforts should include: ● Encouraging political and public health leaders to speak out against stigma.

Continued…

	Recommendation 14 continued: ● Working with community-based organizations to stress to the general and at-risk populations the dangers of risky behaviors in contracting HIV.
Recommendation 15	The State should seek additional resources to broaden the HIV/AIDS prevention approach to encompass other blood-borne pathogens. In doing so highest priority for AIDS Omnibus Act funding should continue to be on HIV/AIDS prevention and education to high-risk populations.
Recommendation 16	The Department and the AIDSNet regions should continue to give priority to prevention interventions that are based on sound evidence or theory.
Recommendation 17	In considering recommendations for statutory or rule changes, the Secretary should ensure they: ● Are scientifically sound. ● Decrease barriers to both providers and clients in the areas of testing and counseling, and diagnosis and care. ● Represent good public health practice.

The Committee finds that:

- The Ellensburg Document was created to help clearly define the roles, responsibilities, and funding targets for prevention services in Washington State, particularly in the face of declining resources. The agreement reinforces and supports the emphasis in the AIDS Omnibus Act on preventing HIV infection and AIDS.

- Stigma and fear associated with HIV in the general population are still obstacles to be overcome, as reported by many with HIV/AIDS and many working in prevention and care. At the same time, public interest in HIV/AIDS has declined over time, as other issues have taken priority.

- The work of the six AIDSNet Regions has become complicated by shifts in the epidemic and social needs not accounted for when the AIDS Omnibus Act was passed, including a rise in other blood-borne pathogens. Many of the populations at risk for HIV infection also are at risk for infection from Hepatitis C virus (HCV) and Hepatitis B virus (HBV).

- In the face of limited resources and increasing need for prevention services, HIV prevention services providers stress that the Department of Health and the AIDSNet regions should continue to give highest priority to HIV/AIDS prevention interventions that have demonstrated success for populations at risk for HIV infection.

HIV Prevention Study Committee Report

Study Mandate

The 2001 Legislature considered Senate Bill 5679, "an Act relating to the HIV/AIDS prevention study committee." The bill stated that the AIDS Omnibus Act of 1988 created a network of HIV/AIDS prevention efforts and programs in Washington State. Since that time, however, the HIV/AIDS "pandemic" had changed. The bill therefore established an HIV/AIDS prevention study committee to evaluate whether management and distribution of funds and resources through the Act remain effective for maintaining current services as well as to meet rising demand and need. The committee's charge was to:

- Review the goals of prevention strategies under the AIDS Omnibus Act in relation to trends in the current epidemic.
- Analyze funding streams and levels for the AIDS Omnibus Act and other HIV/AIDS prevention funding.
- Review the interaction and coordination of HIV/AIDS prevention programs with care services.

The bill required that the committee report its findings and proposed recommendations for updating the AIDS Omnibus Act to the Legislature in January 2002.

The Legislature did not pass the bill. But because need remained for the review and deliberation it outlined, the Department of Health decided to carry forward the intent of the legislation. The Department established the HIV Prevention Study Committee in late-summer 2001, comprising 13 members (listed in Appendix A) with representation as outlined in the original legislation:

- The State Health Officer (Chair)
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The HIV Prevention Study Committee met a total of ten times between August 2001 and February 2002. All committee meetings were open to the public and met the requirements of the Americans with Disabilities Act. Six of the meetings were held in each of the six AIDSNet regions established by the 1988 AIDS Omnibus Act. At each of these regional meetings, the committee heard:

- A presentation by the Department on statewide HIV/AIDS policy and procedures.
- A presentation by the regional AIDSNet on the structure of the region and the epidemiology of the HIV/AIDS epidemic in the region.
- A presentation by representatives of regional HIV/AIDS prevention services planners and providers, including members of the regional planning group and community-based service organizations with which the AIDSNet contracts.
- Public testimony.

At each of the regional meetings the committee asked questions during presentations and testimony, requested additional information from the region or the Department, and discussed the information presented.

The Committee met four additional times to review and discuss what it had heard in the regional AIDSNets and to gain additional information from the Department. The Office of the Superintendent of Public Instruction presented information at one of these meetings.

Members of the Committee also participated in a statewide HIV Policy Summit held in November 2001. Summit planners included representatives of the six regional AIDSNets, community-based organizations, the Governor's Advisory Council on HIV/AIDS, the Department of Health, the University of Washington's AIDS Education & Training Center, and consumers. Committee members presented the Committee's preliminary findings to summit participants and garnered their ideas and suggestions for further consideration.

Findings and Recommendations

The HIV Prevention Study Committee makes 17 recommendations to the Secretary regarding the appropriateness and effectiveness of the 1988 AIDS Omnibus Act for the epidemic as it appears today, in early 2002. The recommendations are supported by the Committee's research findings, and the Committee is unanimous in both the findings and the recommendations. The recommendations are grouped into five categories:

- Recommendations 1-3: Regional AIDSNet Structure
- Recommendations 4-8: Funding and Accountability
- Recommendations 9-10: Education Activities
- Recommendations 11-12: Coordination of Care, Prevention, and Other Related Services
- Recommendations 13-17: AIDS Omnibus Act Policy Support and Changes

In this report the Committee first presents its overall, contextual findings. These are followed by 17 specific recommendations and their supporting findings. A glossary at the end of the report offers definitions for key words and concepts.

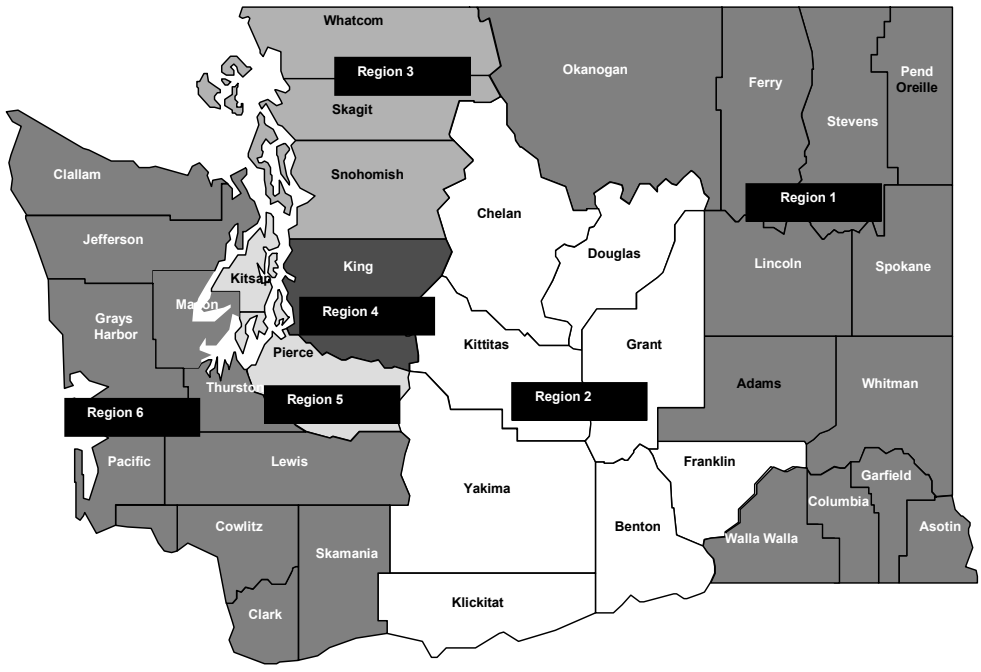
Contextual Findings

The 1988 AIDS Omnibus Act contains visionary provisions for addressing the HIV/AIDS epidemic, including confidentiality assurances; discrimination protections; and education, testing, and counseling mandates. The Act is a living document with built-in flexibility that supports efforts across Washington State to develop and provide prevention and coordination-of-care services for an evolving HIV/AIDS epidemic. Twelve years of working with the Act have shown where its strengths lie, as well as where it can be strengthened.

A Flexible Program for HIV/AIDS Service Planning and Delivery

One of the AIDS Omnibus Act's greatest strengths is its creation of a flexible mechanism for developing, funding, and providing prevention services. The Act created six regional AIDS service networks, or AIDSNets (Figure 1), which are responsible for planning services, identifying populations to serve, and contracting for service provision. This regional structure gives local communities a voice and role in planning, targeting, and providing services to specific populations and needs. The structure has created an environment for effective and supportive collaboration on HIV/AIDS prevention services around the state, particularly among public health agencies and community-based service organizations.

Figure 1: Washington State's Six Regional AIDSNets



Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

Flexible, But Declining, AIDS Omnibus Act Funding

The AIDS Omnibus Act created a flexible funding mechanism that directs funds to each of the AIDSNets to support their work in planning, designing, and providing prevention services. Funding allocated by the Legislature to the Department of Health is channeled to the regional AIDSNets through service contracts with each region's lead county. But AIDS Omnibus funding has not kept pace with service needs. Since 1991, allocated funds have remained flat at $8.1 million, without adjustment for inflation. Consequently, in real dollars AIDS Omnibus Act funding has decreased by approximately 21% since 1990. (For more detailed information, see Recommendation 4 on Page 24.)

While AIDS Omnibus funding has gradually declined over the past 11 years, the number of people infected with HIV has gone up. Deaths from AIDS also have been decreasing, which means more people are living with HIV and AIDS. Thus, declining AIDS Omnibus Act dollars are being spread over increasing numbers of people. The funding decline combined with an increased need for prevention services has resulted in HIV/AIDS planners and providers now having to reduce the array of services they offer.

The Act Supports Coordination of Prevention and Care Services

Although the AIDS Omnibus Act requires that the state provide both prevention and coordination-of-care services, the Act is heavily weighted toward prevention. As the number of people living with AIDS began to grow, the epidemic began to shift from acute to chronic care, making it increasingly necessary to coordinate prevention with care services. Federal funding for prevention services, and accompanying accountability requirements, also emphasize the importance of coordinating these two kinds of services. Through their collaborative work on providing AIDS Omnibus Act prevention services, the regional AIDSNets, local and state public health agencies, and community organizations have developed a shared sense of responsibility for addressing both prevention and care. They currently are working together to create strategies for better coordinating these services.

The HIV/AIDS Epidemic Has Changed Since the Act Was Passed

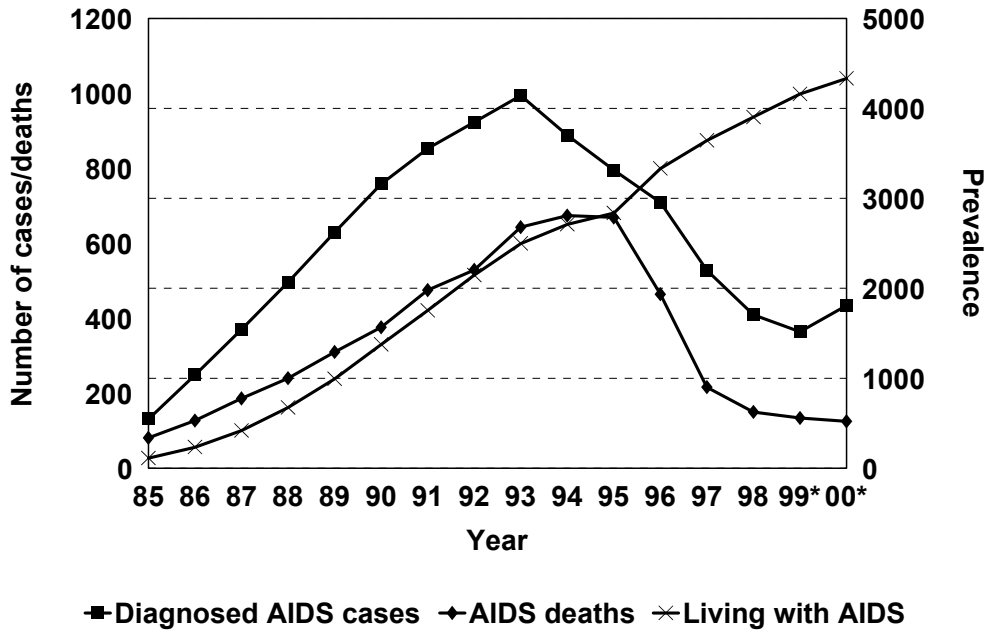
A Growing Number of People are Living with HIV/AIDS

The AIDS Omnibus Act did not, and could not, foresee changes in the HIV/AIDS epidemic that have occurred over the past ten years, including medical advances that have greatly improved the prognosis for people with HIV/AIDS. The number of people diagnosed with AIDS has decreased since the mid-1990s, as has the number of AIDS deaths (Figure 2). Consequently, the number of people living with AIDS (that is, the prevalence of AIDS) has risen steadily, reaching 4,059 people by the end of 2000. Advances in medical care have thereby created a larger population of people for whom prevention services are important: people at risk for HIV infection who need to avoid infection, and people already infected, including those living with AIDS, who need to avoid spreading infection.

The HIV/AIDS Epidemic Has Shifted to Include Other Populations

The largest proportion of HIV/AIDS cases in Washington continues to be in white, gay men, but this proportion has been declining over time. Other populations are making up increasing proportions of those with HIV/AIDS, including women and some racial and ethnic communities. Women made up 4% of cases diagnosed with AIDS in Washington State between 1988 and 1990, but 13% of such cases between 1998 and 2000. Women of color are

Figure 2: AIDS Incidence, Deaths, and Prevalence by Year of Diagnosis, Washington State, 1985-2000



* Case reporting not complete.

Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

disproportionately represented among these cases. Recent case rates (that is, cases per 100,000 population) for African American women, for example, are 22 times higher than for white women. Case rates for Hispanic non-white women are three times higher than for white women, and almost nine times higher for women of American Indian/Alaska Native descent. Recent data for men in Washington State show and AIDS case rate in African American men four times higher than for white men. For Hispanic, non-white men the case rate is double that for white men.

The proportions of AIDS cases due to heterosexual contact and injection drug use also have been increasing. Prevention services providers in many regions of the state also report that they are now serving more clients that face multiple health problems or diagnoses, such as

mental illness and substance abuse, as well as multiple socioeconomic difficulties, such as homelessness and incarceration.

The Impact of the HIV/AIDS Epidemic Varies Across the State

Since 1988, when the AIDS Omnibus Act was passed, Seattle-King County has consistently had the largest proportion of AIDS cases in the state. Over time, however, this proportion has decreased – from 71% in 1988 to 57% in 1998-2000 – as the number of AIDS cases diagnosed in other areas of the state has gone up. Statewide HIV reporting, implemented in late 1999, offers insight into the geographic location of those living with HIV infection that has not progressed to AIDS. These people are closer to the front end – or leading edge – of the epidemic. Data reveal that in 1998-2000 the majority of people diagnosed with HIV in Washington state – 69% – had a King County residence at the time of diagnosis.

Committee Recommendations

Recommendations 1-3: Regional AIDSNet Structure

Recommendation 1: The State should retain the regionalized approach created by the AIDS Omnibus Act to planning HIV/AIDS prevention services.

FINDING: The AIDSNet structure facilitates identifying prevention service needs and ensuring that services are provided throughout Washington State.

The AIDS Omnibus Act, passed in 1988, divided the state into six regional AIDS Service Networks, or AIDSNets, in an effort to provide a system that would most effectively deliver HIV/AIDS prevention services to all Washington State citizens. The AIDSNet regions were based on the State Department of Social and Health Services' six Community Services Administration (CSA) regions as delineated at that time. Today, after nearly 13 years, support within the AIDSNets for a regional service planning and provision structure is strong, though not universal. The regional approach allows for more local control of an infection that is influenced by geographic, demographic, and social and cultural differences around the state. It avoids problems that can arise in applying a broad, statewide approach to smaller, local communities that may have specific and differing needs. The ability to plan and implement services at the local level allows for recognizing the particular social, economic, and demographic factors that influence risk behaviors by local populations.

The regional system has effectively generated and supported collaboration and coordination within the AIDSNet regions, specifically among community based organizations (CBOs) and other service providers. Collaboration between CBOs and local public health is especially important in HIV/AIDS prevention, as it facilitates developing prevention initiatives that cross the boundaries of categorical government programs.

The regional system also provides organizations within a region the opportunity to develop prevention services together. This can enhance the strengths of each organization and identify and fill gaps in services among them; it also allows them to create programs designed specifically to match their region's or community's target populations and needs. Collaborating on programs also helps all the organizations within a region, including local public health agencies, to maximize the financial and personnel resources available to them.

FINDING: The regional system has benefited small communities and rural regions.

The regional system has worked well for all areas of the state, whether an area is urban or rural, or a community is large or small. Within the regional structure, representatives from rural areas and smaller communities have an opportunity to participate in the AIDSNet regional planning process – a process that assesses needs in the overall region, identifies populations at risk, prioritizes populations and prevention interventions, and evaluates the

progress and success of planned prevention activities. Their participation in the planning process also provides them with an opportunity to learn from and share information with other similar communities and with larger, more urban communities, as well.

The regional structure provides opportunities for program development and support for rural and smaller communities with limited resources. In many regions, CBOs and other service providers from smaller and rural communities describe the benefit they receive from working with the expertise, knowledge, and access to resources of their peers from the larger urban centers within their regions. This is critical, as smaller communities often lack the necessary breadth and depth of technical expertise to coordinate all aspects of HIV/AIDS prevention services on their own.

FINDING: The regional system has allowed for maximizing resources and sharing data and information.

Organizations within the AIDSNet regions report that working together to maximize resources – including funding, personnel, and even supplies – has reduced duplication, especially in administrative tasks. This makes more money available for providing HIV/AIDS prevention services. Flat or decreasing funding for prevention services has stimulated some of this merging and sharing of resources. In many cases, the regional approach to providing services also has resulted in people working together more effectively, which has streamlined workflow and enhanced time management.

The regional approach also has stimulated and facilitated sharing of information and data between large and small communities, and urban and rural communities – as well as between AIDSNet regions and the State. This increases all participants' access to more thorough and extensive collections of data. Sharing resources and information between AIDSNet regions, however, is less common overall.

FINDING: The boundaries of the six AIDSNet regions are based on the old Department of Social and Health Services Community Services Administration (CSA) regions. This has complicated coordinating efforts in some ways, particularly in Regions 5 and 6.

The boundaries of the six regional AIDSNets is the subject of some concern, particularly in Regions 5 and 6. The AIDS Omnibus Act designated six regions based on the State's six CSA regions as they existed in 1988 (see Figure 1). These regions not only predated the Act but the Department of Health, as well (which was created in 1989). As one would expect, the CSA regions were not designed to maximize the efficiency or efficacy of delivering HIV/AIDS prevention services. Certain interrelated factors key to the successful delivery of such services – for example, geographic and demographic size of the region; the nature of the populations within the region; location and distribution of higher-density communities; and barriers to accessing and delivering services such as transportation infrastructure and distances – were not considered.

Region 5. Because the CSA boundaries bear no relation to the HIV/AIDS epidemic, they have in some ways complicated efforts to provide and coordinate services for Regions 5 and 6. Region 5 encompasses two counties: Kitsap and Pierce. Although both have a fairly high-

density population overall, Pierce has the high-density City of Tacoma and its suburban environs, whereas the population in Kitsap is more dispersed and lacks an established urban center. HIV/AIDS service providers report that the face of the HIV/AIDS epidemic in the two counties is, consequently, quite different. Appropriate prevention strategies and interventions in the two counties are, therefore, different as well.

At this time, Kitsap and Pierce counties see themselves as being too inherently different to work together effectively within the same AIDSNet region. The counties act almost independently of one another regarding HIV/AIDS prevention services, with very little communication or coordination between them. Each has its own independent regional planning group, and thus its own regional planning process. The Puget Sound crossing between the two counties also apparently serve as both a physical and psychological barrier to traveling between them for receiving services.

Region 6. Region 6 comprises 11 counties, from Clallam in the north to Clark in the south, encompassing a range of geographic, demographic, and social and cultural population differences (see Figure 1). Prevention and care service providers in Jefferson and Clallam counties observe that the populations they serve have more in common with neighboring Kitsap County, in Region 5, than with populations in other counties in Region 6.

The relationship between Clark County and Portland, Oregon, is a significant complication to coordinating HIV/AIDS prevention services in Region 6. Clark County falls within the Portland eligible metropolitan area (EMA) designated by the federal Health Resources and Services Administration (HRSA) under Title I of the Ryan White CARE Act (1990; 1996; 2000). EMAs are targeted to receive Ryan White HIV/AIDS care funding. Clark County's participation in the Portland EMA presents some difficulties for the region:

- The HIV/AIDS prevention services priorities of Region 6 – and of Washington State – often are different than those of the Portland EMA.
- The Southwest Washington Health District, which is the lead agency for this AIDSNet region, must participate in two separate HIV/AIDS planning processes.
- CBOs in Clark County must simultaneously meet the requirements of both the Portland EMA and the Region 6 AIDSNet.
- Care and affiliated programs offered by the Portland EMA are provided in Portland, and access to the city can be difficult for some of the targeted populations in Clark County.
- Sorting out funding streams and their related services between the EMA and the Region 6 AIDSNet can be difficult.

All of these coordination issues between Clark County and the Portland EMA affect the County's participation with the other ten counties in this AIDSNet region, particularly when it comes to assessing prevention and care needs in the overall region, identifying populations at risk, and prioritizing target populations and prevention interventions.

Recommendation 2: The Secretary should have authority to designate no less than five, and no more than ten, AIDSNets regions. In designating the regions, the Secretary should consider, at a minimum:

- **Existing preventive service partnerships**
- **Patterns of travel and care**
- **Regional epidemiology**

Any re-evaluation of the AIDSNet regional boundaries would need to consider existing collaborative efforts and preventive service partnerships within the current regions. Collaborations among community-based organizations, other service providers, and local public health for the delivery of services within the existing regions are common and effective. Mutual support is strong between programs and organizations within the regions. Service providers and stakeholders in the communities highly value community participation in the regional planning process and in service provision. Collaboration and mutual support allow the regions to target populations they otherwise could not and help to compensate for limited resources. In some cases collaborative efforts among community-based organizations supercede regional boundaries and form across several areas of the state.

A re-evaluation of the AIDSNet boundaries also would need to consider existing patterns of travel to receive and provide services within the regions. These patterns are pivotal to determining how and where prevention services are delivered and received within populations. Transportation issues, such as distances that clients and providers must travel, are a barrier to providing effective HIV/AIDS prevention services in several regions. Both access to transportation and type of transportation will largely determine the patterns people establish for receiving care and prevention services. Transportation and access issues within the AIDSNet regions are greatest in rural areas and small communities. Service providers in Region 2, for example – which encompasses Chelan, Douglas, Kittitas, Grant, Yakima, Klickitat, Benton, and Franklin counties (see Figure 1) – assert that transportation and access issues are "nearly insurmountable." Physical barriers in a region, such as the Puget Sound separating Kitsap from Pierce County, also influence where people will seek prevention services by exacerbating transportation problems.

Re-evaluation of the AIDSNet boundaries also will need to consider the epidemiology of HIV/AIDS in the regions. The epidemic has shifted to include populations other than white, gay men, including more women and people of color. The proportions of cases due to heterosexual contact and injection drug use also have been increasing. And the number of Washingtonians with living with HIV/AIDS is increasing. In addition, there are regional differences in the impact of the epidemic. The proportion of AIDS cases diagnosed in areas of the state outside of Seattle-King County has been increasing since 1990.

Redefining the AIDSNet boundaries has some precedent. The Southwest Washington Health

District, which at one time comprised Skamania, Clark, and Klickitat Counties, is the lead public health agency in the Region 6 AIDSNet. In 1998, Klickitat County established its own county health department, withdrawing from the Health District. At that time the State Department of Health, the regional AIDSNet directors, and local county public health officials agreed that because of its location and orientation more to the east side of the Cascades, Klickitat County would be better served by becoming part of the Region 2 AIDSNet.

Recommendation 3: The State should retain the regional flexibility provided by the AIDS Omnibus Act for implementing HIV/AIDS prevention efforts.

FINDING: The overall flexibility provided by the AIDS Omnibus Act has worked well for those implementing it.

One of the AIDS Omnibus Act's greatest strengths is its creation of a flexible mechanism for developing, funding, and providing prevention services. The regional approach gives local communities a voice and role in planning services, identifying populations for whom services will be provided, and contracting for service provision. This approach also provides a structure that has the ability to address the epidemiology and demography of the HIV/AIDS epidemic at the local level. Cultures, attitudes, and the extent of the epidemic differ in various regions in the state, particularly between urban and rural areas and among risk groups. Each AIDSNet region faces a mix of prevention issues and at-risk populations. The flexibility the Act affords each region in targeting populations and providing prevention services is critical to meeting the needs of different communities.

Recommendations 4-8: Funding and Accountability

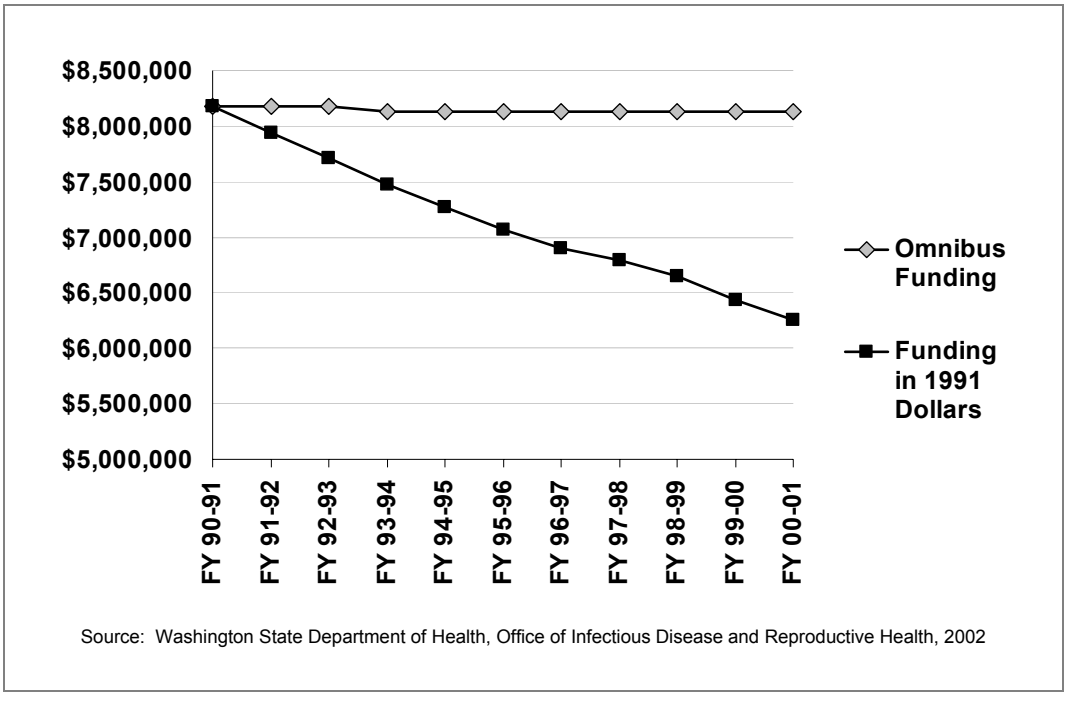
Recommendation 4: The Legislature should strive to restore AIDS Omnibus Act funding to the equivalent of 1991 levels, but at a minimum maintain current funding for HIV/AIDS prevention.

FINDING: AIDS Omnibus Act funding and the funding allocation scheme have worked well, for the most part, over the past 12 years. But adjusting for inflation reveals that Omnibus Act funding has decreased by approximately 21% since 1990. At the same time, the need for prevention services has risen. Fewer and fewer dollars now must be spread over a greater number of people, and AIDS Omnibus Act funding has become insufficient to meet the need for prevention services.

AIDS Omnibus Act funding is allocated by the Legislature to the Department of Health through the state's biennial budget. The Department channels all but approximately 1% of the funds to the regional AIDSNets through service contracts with each region's lead county. The total funds contracted to each region are determined by an allocation formula.

Since fiscal year 1990-1991, AIDS Omnibus funding has remained flat at $8.1 million annually – it has never been adjusted for inflation. Consequently, in real dollars this funding has decreased by approximately 21% since 1990 (Figure 3). Over this same period, people

Figure 3: The Value of AIDS Omnibus Funds Based on the Consumer Price Index, 1990-2001

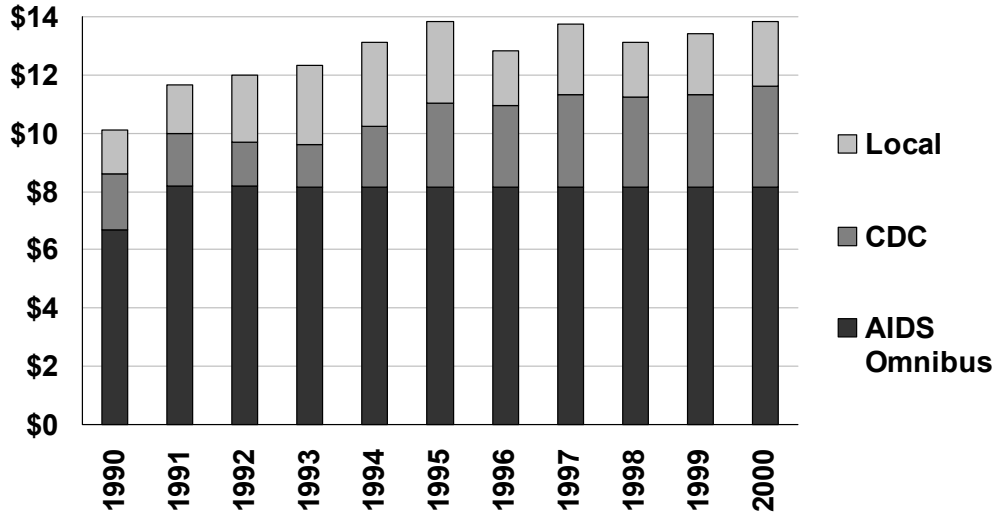


Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

have continued to become infected with HIV, and in some the infection has progressed to AIDS. But deaths from AIDS have declined in Washington State (see Figure 2), meaning more people are living with HIV and AIDS. From the end of 1991 to the end of 2000, the number of people presumed to be living with AIDS in Washington State increased nearly four-fold, from 1,081 to 4,059 (as calculated by the Department of Health). For just this population – that is, not also considering people infected with HIV and people at risk for HIV infection – the 1991 AIDS Omnibus dollar must now be spread over four times as many people, even without adjusting for inflation.

Since the mid-1990s, AIDS Omnibus Act funding has accounted for approximately 57% of the dollars used statewide for HIV/AIDS prevention services. As the real value of these dollars declined, prevention funding the state received from the CDC increased: from $2 million in 1994 to $3.9 million in 2000. Although CDC funds have kept pace with inflation, now comprising about 25% of the state's total prevention funds, they have not made up for the shortfall in the state's AIDS Omnibus funding. The remainder of the state's prevention services funding is made up of local, tax-based support (Figure 4).

Figure 4: Total AIDS Omnibus Act, Federal CDC, and Local HIV Prevention Funding, 1990-2000 *(in millions)*



Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

With the convergence of declining funding in terms of real dollars and increasing need, any further reduction in the Legislature's AIDS Omnibus Act funding allocation could reduce the populations the Department and the regional AIDSNets serve and the prevention services they provide. This, in turn, could lead to increased incidence of HIV infection across the state. The state can choose to spend dollars on prevention services now, or care services later. According to the Center for AIDS Prevention Studies at the University of California,

San Francisco, successful HIV prevention programs that are targeted to the correct populations can be highly cost-effective. One million dollars spent on HIV prevention can save $2.7 million, depending on HIV prevalence in the population targeted. In an age of budget tightening, HIV prevention can help to more effectively spend limited funds, save lives, and impact the course of the AIDS epidemic.[1]

FINDING: A reduction in AIDS Omnibus Act funds could reduce federal Medicaid matching funds for AIDS case management.

Persons with AIDS who are enrolled in the state's Medicaid program are provided case management services funded from AIDS Omnibus Act funds that are matched dollar-for-dollar by federal Medicaid funds. These combined dollars are an important funding source for local health departments and service organizations within the regional AIDSNets. Reducing the AIDS Omnibus Act allocation from the Legislature could put state funding for Medicaid AIDS case management in jeopardy. At the least, Omnibus Act dollars dedicated to these services could be reduced, and for each dollar of Omnibus funds reduced one dollar of federal Medicaid matching funding would be lost. An alternative approach would be to fund Medicaid case management through the Department of Social and Health Services budget instead of through the Omnibus Act.

Recommendation 5: The Department should retain the AIDS Omnibus Act's emphasis on using resources for HIV/AIDS prevention.

FINDING: Since passage of the AIDS Omnibus Act, the federal government has substantially increased its support of HIV/AIDS clinical care and has somewhat increased its support for prevention services, though federal support for both comes with some restrictions.

The AIDS Omnibus Act is the primary source of funds in Washington State for HIV/AIDS prevention services, comprising approximately 57% of the budget (see Figure 4). The Act requires that the state provide both prevention and coordination-of-care services, but is heavily weighted toward prevention. Each AIDSNet region, for example, must develop a regional service plan that includes:

Prevention Services

- Voluntary and anonymous counseling and testing.
- Mandatory testing and/or counseling for certain individuals, as required by law.
- Notification of sexual partners of infected persons, as required by law.
- Education for the general public, health professionals, and high-risk groups.

[1] Kahn JG. The cost-effectiveness of HIV prevention targeting: how much more bang for the buck? Presented at Targeted and Universal Approaches to Reducing the Risk of HIV Transmission, New York; 1994. See http://www.caps.ucsf.edu/

- Intervention strategies to reduce the incidence of HIV infection among high-risk groups.
- Related community outreach services for runaway youth.
- Case management [for example, assisting clients in accessing prevention services]
- Strategies for developing volunteer networks.
- Strategies for coordinating related agencies with the AIDSNet.

Coordination-of-Care Services

- Case management [for example, assisting clients in accessing care services]
- A community-based continuum-of-care model encompassing both medical, mental health, and social services.

The federal government is more focused on funding HIV/AIDS care than on funding prevention services. In 2000, for example, approximately 71% of all federal HIV/AIDS spending nationally was on care and assistance, compared to about 8% on prevention.[2] Federal funding to Washington state for care and assistance through Titles I and II of the Ryan White CARE Act has increased by approximately 137% since 1993 (outpacing inflation, which rose by approximately 23% between 1993 and 2001). Total funding to the state through these Titles, which is pooled and used for both state and local HIV/AIDS care programs, was more than $8 million in 2001. This is more than twice the funding the federal government gives to the state, through the CDC, for HIV/AIDS prevention services. In 2000, the state received $3.9 million from the CDC, an amount that comprised 25% of the state's prevention budget. In addition, for both care and prevention the federal dollars come with substantial guidelines and restrictions that limit the populations and services they support.

Over time, the AIDS Omnibus Act's emphasis on prevention has corresponded well with the state's growing need for prevention services – but state funding allocated to implement the Act has not. By 1997, the Department and leaders of the regional AIDSNets and local communities recognized that in the face of limited and declining resources they needed a commitment to statewide regional consistency in the allocation of funding to prevention services. Together, they developed a letter of understanding – the "Ellensburg Document" – (signed in 1999) that directs that:

- 50% of AIDS Omnibus Act funds within each AIDSNet region must be used to address the priorities established by the regional planning process.
- 100% of the state's CDC prevention funds must be used for priority prevention services by the Department and the regional AIDSNets.
- Up to 10% of the state's CDC prevention funds may be set aside by the Department for statewide unmet prevention service needs.

The Ellensburg Document reinforces and supports the emphasis in the AIDS Omnibus Act on HIV/AIDS prevention services. Both documents are founded on the importance of

[2] Foster, S. and P. Niederhausen. Federal HIV/AIDS Spending: A Budget Chartbook, Fiscal Year 2000. Third Edition. The Henry J. Kaiser Family Foundation; 2000.

preventing infection, particularly in high-risk populations, rather than facing the personal and financial costs of treatment. The Act's weighting of resources toward HIV/AIDS prevention activities has served, and will continue to serve, as a counterbalance and complement to the federal government's stronger emphasis on HIV/AIDS care.

Recommendation 6: The Department should revise the current AIDSNet funding allocation formula, developed in 1995. Factors that should be used to revise the formula include, at a minimum:

- **HIV reporting data**
- **Increased incidence and prevalence of HIV/AIDS in racial/ethnic communities**

FINDING: Washington State has now instituted HIV reporting, in addition to AIDS reporting, which will provide more timely and accurate data about changes in the epidemic.

Reporting of HIV cases in Washington State began in September 1999. Reporting will help to assess the prevalence of HIV cases over time, especially the demographics and geographic patterns of the infection. HIV reporting cannot tell us, however, the number of new cases that occur within a given time period – that is, the incidence of the infection. This is because HIV reporting occurs only at the time a person gets tested, not when a person becomes *newly* infected. A person's infection at the time of testing could be weeks, months, or years old. Hence, for several years (and in the absence of more sophisticated laboratory tests) HIV reporting data cannot be interpreted as telling us about *new* trends in the epidemic.

HIV reporting also does not identify all HIV cases in the population. People who tested positive for HIV prior to September 1999 will not show up in the data until they take the test again or seek medical care. People who test in another state, with a home test kit, or test anonymously also will not be recorded. Finally, there are people who have not yet been tested who are infected with HIV. Consequently, it is likely that reported HIV cases are, and will be, below the actual number of cases in the population.

Any re-examination of the current AIDSNet funding allocation formula should consider how HIV reporting data, coupled with estimates of under-reported and untested individuals, might be used.

FINDING: The current formula for allocating funds among the regions does not adequately reflect the changed demographics of the epidemic.

The HIV/AIDS epidemic has changed in Washington State since 1995, when the current formula used to allocate funds to the six regional AIDSNets was developed. The formula gives most weight to the size of a region's population overall and the predominance in the

population of men who have sex with men – both in the total number and the number of AIDS cases among them (Table 1). Together, these three factors account for 60% of the formula. Among the other seven factors, 15% accounts for the number of intravenous drug users in the population; 5% for the proportion that is African American and/or Hispanic, and 2.5% for the number of women of child-bearing age.

Table 1: AIDS Omnibus Act Regional AIDSNet Funding Formula (1995)

30.0%	Size of region's population
15.0%	Estimate of the number of men who have sex with men within the region
15.0%	Number of AIDS cases among men who have sex with men within the region
15.0%	Number of AIDS cases among intravenous drug users within the region
10.0%	Proportion the region accounts for the statewide increase in AIDS cases
5.0%	Size of the region's African American and Hispanic populations
2.5%	Proportion of the region's female population that is of child-bearing age
2.5%	The region's teen pregnancy rate
2.5%	Proportion of the region's population that is rural
2.5%	Proportion of the region's population that has Hepatitis B

The 1995 allocation scheme no longer reflects the demographics of the epidemic. For example, AIDS case data indicate three characteristics of the current epidemic in Washington State:

- **Although the largest proportion of HIV/AIDS cases continues to be in white, gay men, this proportion has been declining over time.** Other populations have been making up increasing proportions of those with HIV/AIDS, including women and people of color.
- **The number of people living with HIV/AIDS continues to grow.** The number of people living with AIDS in Washington (that is, the prevalence of AIDS) has risen steadily since 1985, reaching 4,059 people by the end of 2000. Through the end of 2001 the estimated total number of people living with HIV, including those with AIDS, is 7,240.
- **The proportions of cases due to heterosexual contact and injection drug use have been increasing.**

The Department currently is supporting the work of a committee in developing a new allocation formula that would better reflect the changed demographics. Factors the committee is considering for the new formula include:

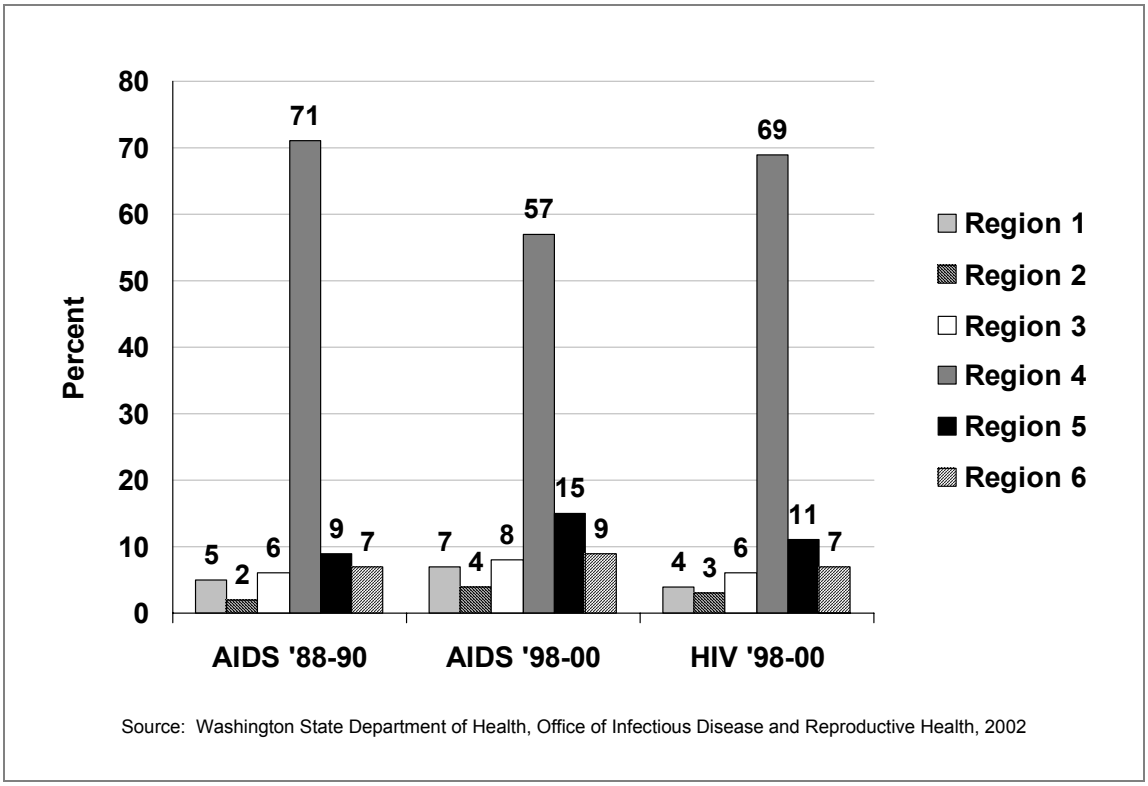
- Total population within an AIDSNet region
- Disproportionate impact of HIV on people of color
- Total population in the region living with HIV/AIDS
- Number of new cases of HIV in the region over a given period of time (that is, HIV incidence)

FINDING: The current formula for allocating funds among the regions does not adequately address population shifts among regions.

AIDS case data indicate that the geographic distribution of AIDS cases is shifting somewhat. Between 1988 and 1990, the largest proportion of AIDS cases – 71% – lived in the Seattle-King County area, which comprises Region 4, at the time of their diagnosis. This proportion decreased to 57% between 1998 and 2000, as a growing proportion of AIDS cases have been diagnosed in areas outside of Seattle-King County (Figure 5). For example, Region 5, comprising Pierce and Kitsap counties, gained six percentage points between 1988 and 2000; the remaining regions each gained two. Still, 69% of people diagnosed with HIV between 1998 and 2000 had a King County residence at the time of diagnosis.

AIDSNet service providers in some regions report that there has been a migration of people with HIV/AIDS from urban to rural areas. Some service providers have clients who reside in rural areas now, but lived in the urban center of another county when they received their diagnosis. Because HIV/AIDS reporting is based on county of residence at the time of diagnosis, these people are included in the other counties' case rate data. This "case migration" is not factored into the Department of Health's allocation of AIDS Omnibus funds. Case migration has more of a fiscal impact on care services, than on prevention services.

Figure 5: HIV and AIDS Cases by AIDSNet Region and Year of Diagnosis, Washington State (cases reported as of 5/31/01)



Source: Washington State Department of Health, Office of Infectious Disease and Reproductive Health, 2002

AIDSNet service providers also report that some persons at risk for HIV infection, particularly men who have sex with men, go to neighboring urban centers to engage in high-risk activities (such as unprotected sex and drug use). This can hamper one region's efforts at providing prevention services, and increase the need for such services in another.

The factors currently being considered for a new funding allocation formula include the total population in an AIDSNet region living with HIV/AIDS and the number of new cases of HIV in a region over a given period of time (HIV incidence). These factors could help to reflect population shifts among regions.

FINDING: The current formula for allocating funds among the regions does not adequately account for the greater difficulty in targeting rural at-risk populations.

AIDSNet leaders and service providers report that targeting rural at-risk populations is fraught with difficulties and, therefore, is more expensive than targeting urban populations. They argue that the current AIDS Omnibus Act funding allocation formula does not adequately finance this work in rural areas, a condition exacerbated by the overall decline in funding. Barriers to identifying and providing services to people in rural areas include:

- Stigma and fear among the general population, which inhibit people from seeking counseling, testing, and clinical care services.
- A dispersed population, without the gathering spots found in more urban areas.
- A migrant population, many of whom do not speak English as their first language and do not seek services out of fear or from lack of knowledge of their existence.
- Greater travel distances to provide services.

The factors being considered for a new funding allocation formula do not, at this time, take into consideration the proportion of the population within an AIDSNet region that is considered either urban or rural.

FINDING: The current formula for allocating funds among the regions does not adequately account for the larger number of cases and likelihood of transmission in urban areas.

Urban AIDSNet regions report that the current funding formula does not adequately account for their having a larger population overall or for the associated greater likelihood of higher infection transmission rates. They also point out urban areas incur higher costs for salaries and overhead expenses (such as rent).

The factors being considered for a new funding allocation formula include the total population in an AIDSNet region, the total population in the region living with HIV/AIDS, and the number of new cases of HIV in the region over a given period of time. These factors could help to better reflect the larger number of cases in urban areas, and the higher likelihood of infection transmission.

Recommendation 7A): The regional AIDSNets should provide annual, comprehensive fiscal and activity reports to the Department and the community. The reports should be consistent across all regions. At a minimum, they should include:

- **A breakdown of AIDS Omnibus Act funding by the type of service and population targeted.**
- **A listing of each service provider contract with the dollar amount and time frame of the contract.**
- **A disclosure of the amount of AIDS Omnibus Act funds being retained by each service provider for overhead and/or indirect costs.**
- **A breakdown of administrative costs for the AIDSNet administrative agency.**
- **A listing of funding received through Titles I and II of the Ryan White CARE Act, the services it was allocated to, the providers to whom it was allocated, and the amount per provider. (These reports would not include funding to agencies received independently through Titles III and IV of the Ryan White CARE Act or directly from the CDC within the AIDSNet region.)**

Recommendation 7B): The Department should analyze and evaluate data from the regional AIDSNets on administrative, overhead, and indirect costs and provide feedback to stakeholders and interested state agencies comparing administrative, overhead, and indirect charges across the regional AIDSNets.

FINDING: The relationship between DOH and the AIDSNets is generally quite strong. Reporting standards, especially regarding the use of funds, should be improved.

The AIDS Omnibus Act did not clearly define and describe accountability between the Office on AIDS (in the Department of Health) and the AIDSNet regions. The Department and the AIDSNets have created a program monitoring system – the Statewide HIV Activity Reporting and Evaluation system, or SHARE – that incorporates information on funded HIV/AIDS health education and risk reduction activities (HE/RR). The database does not, however, include line items for dollars assigned to or expended for services in each region. Fiscal reporting to the Department – either as the proportion of allocated funds a region expects to spend in certain areas or as actual contract and staff expenditures – is not consistent across the regions.

Some stakeholders within the AIDSNet regions, including community-based organizations that contract with the regions, would like to see consistent reporting to the Department and the community from each region on expenditures for prevention services, care programs, services and programs mandated by the Act, and administration. Consistent reporting from

each AIDSNet region would provide a tool for the Department to ensure accountability for AIDS Omnibus Act spending statewide. Accountability also would be enhanced by the Department providing analysis and feedback to the regions on the data it receives.

FINDING: The AIDS Omnibus Act functions in concert with two other federal planning processes that have, over time, created more complex and demanding HIV/AIDS services planning. Developing multiple state and federal plans, each with a different fiscal year, is an administrative burden for the AIDSNets and the Department of Health.

The growing complexity of HIV/AIDS services planning, which includes federal and state processes that are not jointly timed, has become particularly burdensome for smaller public health agencies and their collaborating community-based organizations. AIDSNet service providers report that the growing complexity has begun to inhibit participation by HIV/AIDS-affected communities and that new community-based organizations are finding it increasingly difficult to break into the process. At times, the planning process has taken so long that the people in need of services have changed by the time the service plan is implemented.

All of these concerns reflect the contention from service planners in some smaller communities that the planning process has become too costly in personnel time and program financial resources. As a consequence, the AIDSNets are more and more concerned, and vociferous, about the administrative burden they and their contractors bear. Feedback from the Department that compares administrative, overhead, and indirect charges across the AIDSNet regions would give the regions and their contractors information to help them evaluate and in some cases effectively reduce their level of administrative burden.

Recommendation 8: The Secretary should direct regional AIDSNets to implement programs for specific at-risk populations in communities that are unable to target these populations.

AIDSNet leaders and service providers in rural areas of the state report that targeting rural at-risk populations is fraught with difficulties and is more expensive than targeting at-risk people in urban populations. Some assert that their funds are better spent on the populations they can more readily identify and serve.

The Ellensburg Document, to which all the AIDSNet regions, community planning groups, and the Department of Health are signatories, stipulates that 50% of AIDS Omnibus Act funds within each AIDSNet region must be used to address the priorities established by the regional planning process. If communities are unable to target at-risk populations identified by this process, the regional AIDSNet lead agency should take responsibility for implementing programs for these populations across the region. This might mean that the lead agency retains funding to support this work.

Recommendations 9-10: Education Activities

Education remains a critically important aspect of preventing the spread of HIV infection, especially in the face of an upturn in risk-taking behaviors and a downturn in interest and knowledge among the general population. HIV/AIDS prevention and care service providers report that over time, people at risk for HIV infection and those who are already infected or are living with AIDS have become less careful in behaviors that can lead to the spread of HIV – they are taking more risks. The new treatments available for AIDS have contributed to this decline in vigilance and in public interest in the HIV/AIDS epidemic, as well. Other social issues have taken priority as the general public incorrectly assumes that the AIDS epidemic is under control and the disease is no longer deadly. Many working in prevention and care, and many people living with HIV/AIDS, report that the stigma and fear associated with HIV/AIDS in the general population remain obstacles that must be overcome.

Recommendation 9: The Secretary should work with the Superintendent of Public Instruction to develop a method of accountability, including outcome measures, that will ensure the consistent provision and quality of HIV/AIDS education across public schools.

FINDING: The education mandate in the AIDS Omnibus Act provides sufficient direction and guidance for implementing HIV/AIDS educational programs throughout Washington, but the Act lacks an assurance mechanism.

The AIDS Omnibus Act is thorough and inclusive in the populations for whom it requires HIV/AIDS education, including:

- Grades 5-12, college, university, and trade school students
- Emergency medical personnel
- Health and pharmacy professionals
- Public school employees
- Government employees
- Health care facility employees
- General public

The Act mandates that HIV/AIDS education be included in the basic Grade 5-12 curriculum, and that it be provided at least once a year. It specifies that the AIDS prevention curriculum should include describing the dangers of drug abuse, especially involving hypodermic needles, and the dangers of sexual intercourse with or without condoms (RCW 28A.230.070 (6)). But the Act does not require that the content and emphasis of HIV/AIDS education be standardized across school districts.

In providing HIV/AIDS education, school districts can use a model curriculum developed by

the Office of the Superintendent of Public Instruction (OSPI) or develop their own. If they choose the latter, the Act mandates that they must submit their proposed curriculum to the Department of Health to be checked for medical accuracy – a process that is widely supported among HIV/AIDS stakeholders. The OSPI has found that communities tend to accept curricula that have been developed exclusively by and for their population.

In addition to there being no required standard educational content for Grades 5-12 statewide, children are not required to attend the educational sessions that are offered. The AIDS Omnibus Act provides an "opt-out" clause that allows parents to chose to remove their children from the HIV/AIDS education program offered in school. Parents must review the curriculum, however, before they can opt their children out. Overall, the opt-out rate is very low. In addition to children who are "opted out," growing numbers of children are home schooled and are not required to receive this education.

Because of the content of HIV/AIDS education, some school districts have asked local public health departments to provide HIV/AIDS education in the classroom. Public health funds support this education in some cases; in others, school districts reimburse the health department. This too, works against a consistent message being delivered to children across the state.

Developing a method of accountability for all school districts will go far in ensuring that children across the state's public schools are receiving HIV/AIDS education that is consistent and of high quality.

Recommendation 10: The Department should promote consistent, regular, risk-targeted education and training in the criminal justice system.

FINDING: The AIDS Omnibus Act includes many more specific requirements about general education than about risk-targeted education.

Almost a quarter of the AIDS Omnibus Act deals with education mandates covering much of Washington State's population, including children, emergency medical personnel, health professionals and staff, public school and other government employees, and the general public. HIV/AIDS prevention services providers feel, however, that the Act does not place sufficient emphasis on education for high-risk populations, including people in drug treatment centers, mental health programs, and homeless shelters, among others. Some AIDSNet providers assert that using Omnibus Act funds for general education diverts them from targeting those at higher risk.

The Act specifically addresses education for high-risk populations in these sections:

- **RCW 70.24.360** Jail detainees -- Testing and counseling of persons who present a possible risk

- **RCW 70.24.370** Correction facility inmates -- Counseling and testing of person who presents a possible risk -- Training for administrators and superintendents -- Procedure
- **RCW 70.24.400** **(3)(iv)** Education for the general public, health professionals, and high-risk groups.

  (3)(v) Intervention strategies to reduce the incidence of HIV infection among high-risk groups, possibly including needle sterilization and methadone maintenance.

HIV/AIDS prevention services providers report that training for corrections facility staff, who deal with a high-risk population, is an area that has proven to need more emphasis.

Recommendations 11-12: Coordination of Care, Prevention, and Other Related Services

Recommendation 11: The Department and the regional AIDSNets should seek out and develop more mechanisms for interaction and collaboration between care and prevention services.

FINDING: Interaction and coordination among HIV/AIDS prevention programs and care services is increasing as a result of identified needs, especially where clients face multiple problems such as homelessness, mental illness, substance abuse, and incarceration. But financial and system barriers to coordinating such services remain.

AIDSNets, local and state public health agencies, and community organizations have a shared sense of responsibility for addressing both HIV/AIDS prevention and care. The AIDS Omnibus Act delegates this responsibility to the regions by requiring that their service plans include:

- **RCW 70.24.400(3)(c)(ii)** A community-based continuum-of-care model encompassing both medical, mental health, and social services with the goal of maintaining persons with AIDS in a home-like setting, to the extent possible, in the least-expensive manner

The Act did not foresee the dramatic improvement in treatment options and the longer lives that people with HIV/AIDS now experience. Hence, the goal laid out by the Act for the continuum-of-care model, which focuses on the much shorter life span anticipated for people living with AIDS in 1988, is quite dated. Today, coordinating prevention with care includes the important goal of providing prevention services to a much larger population of people already infected who need to avoid spreading infection.

The HIV/AIDS epidemic has shifted to include populations other than white, gay men, including more women and people of color. The proportions of cases due to heterosexual contact and injection drug use also have been increasing. These changes in the epidemic have altered the types of prevention services needed, how and where they are provided, and how they are coordinated with care services. Cultures and attitudes toward HIV/AIDS, which can differ between urban and rural areas and among risk groups, further complicate the coordination of prevention and care efforts.

Prevention and care services also have become more complicated to plan and provide over time as federal and state funding requirements have increased and become more complicated to coordinate. The regional AIDSNets must meet the requirements of Titles I and II of the Ryan White CARE Act for HIV/AIDS care services funds and the CDC's community planning model requirements to receive federal prevention services funds. They also must

meet the requirements of the state's AIDS Omnibus Act to receive state prevention services funds. AIDSNet administrators and service providers report that in some ways, the added complexity and demands of meeting the requirements of several funding sources (often referred to as "categorical funding streams") have led to improvements in HIV/AIDS prevention and care coordination, such as more targeted interventions and better coordination of services. But at the same time, some of the federal funding requirements have inhibited service planners' and providers' ability to integrate these services.

The changing nature of the epidemic and increasingly complicated funding requirements are barriers to successfully coordinating prevention and care services, but the efforts of service providers and policy makers across the state have shown that they are not insurmountable. By continuing to seek out and develop more mechanisms for interaction and collaboration between care and prevention services, the Department, the AIDSNets, and community organizations will meet with even greater success.

FINDING: The overall complement of staff within care organizations is less likely to mirror the client population demographically than are the staff in prevention organizations. This makes coordinating prevention and care more difficult and can be a barrier to people receiving services.

Providers of HIV/AIDS prevention services, especially where prevention and care are administered separately, report several barriers to coordinating prevention and care that are specific to care providers and case workers. In many cases they:

- Do not mirror the populations they serve as well as do prevention services providers.
- Do not have the time to offer prevention services or the skills to do so.
- Do not know what prevention resources are available.

Prevention service providers suggest that one way to improve prevention and care services coordination would be to develop a mechanism for community members and program clients to become involved in evaluating coordinated prevention and care programs. This could help ensure adequate feedback about the effectiveness of coordinated services for targeted populations.

Recommendation 12: The Department, other appropriate state agencies, regional and local policy makers, prevention services providers, and activists should seek out and develop mechanisms to appropriately address co-morbid factors – such as homelessness, intravenous drug use, mental illness, and poverty – to maximize the efficacy of limited HIV prevention resources to address these factors.

FINDING: The number of HIV infected persons affected by complicating co-morbidities (illnesses), such as homelessness, mental illness, and substance abuse, is increasing.

Prevention service providers report that HIV/AIDS cases are becoming increasingly complex, and many people who are infected with HIV now require a wider range of social services in addition to basic HIV/AIDS prevention services. The number of HIV positive persons affected by other social and health factors (co-morbidities) such as homelessness, mental illness, and substance abuse is increasing. These issues must be addressed for prevention efforts to be successful. As suggested by one prevention service provider: a person who does not have a place to sleep at night has more concerns on his mind than worrying about whether he has disinfected the needle he is about to use.

The AIDS Omnibus Act requires that each AIDSNet region's service plan include a community based continuum-of-care delivery model that encompasses medical, mental health, and social services. But at the same time that the need for addressing co-morbidities has been increasing, funding allocated through the Act has declined (by 21% in real dollars – see Recommendation 4 on page 24). The Department and the regional AIDSNets need to develop strategies to address these complicating factors without further stretching HIV/AIDS prevention funding. Two possible strategies are:

- Identify and use current community and social resources.
- Develop a way to unify community and social resources, possibly by establishing a coalition that brings together diverse constituents.

Recommendations 13-17: AIDS Omnibus Act Policy Support and Changes:

Recommendation 13: The Secretary should continue to support the Ellensburg Document and ensure that its principles remain in effect as an appropriate and successful mechanism for targeting funding and services to at-risk populations.

The Ellensburg Document was developed in late 1998 by the Department of Health, representatives of the regional planning group in each AIDSNet region, the AIDSNet Council, and the statewide HIV prevention planning group. By mutual agreement, the document sets the framework and context for HIV prevention planning in the state. It sets out the responsibilities of the four major actors in prevention planning, including:

- Regional Planning Groups (RPG)
- Regional AIDSNets
- State Planning Group (SPG)
- Department of Health

The Ellensburg Document also directs how HIV/AIDS prevention funding allocated to the AIDSNets by the Department should be spent:

- 50% of AIDS Omnibus Act funds within each AIDSNet region must be used to address the priorities established by the regional planning process.
- 100% of the state's CDC prevention funds must be used for prevention services by the Department and the regional AIDSNets.
- Up to 10% of the state's CDC prevention funds may be set aside by the Department for statewide unmet prevention service needs.

Washington State provides more funds for HIV/AIDS prevention services than do many other states. But since 1990, AIDS Omnibus Act allocations have not kept apace with either cost inflation or the increase in HIV/AIDS cases. The Ellensburg Document was created to help clearly define the roles, responsibilities, and funding targets for prevention services in Washington State, particularly in the face of declining resources. It reinforces and supports the emphasis in the AIDS Omnibus Act on preventing infection. Supporting the Ellensburg Document will bolster its acceptance as an appropriate and successful mechanism for targeting funding and services to at-risk populations.

Recommendation 14: Because HIV/AIDS stigma still exists, the Secretary should strongly support the privacy and confidentiality elements of the AIDS Omnibus Act, and should sponsor and support efforts to reduce stigma. Efforts should include:

- **Encouraging political and public health leaders to speak out against stigma.**
- **Working with community-based organizations to stress to the general population and at-risk populations the dangers of risky behaviors in contracting HIV.**

FINDING: Stigma and fear associated with HIV in the general population are still obstacles to be overcome, as reported by many with HIV/AIDS and many working in prevention and care.

The Washington State HIV/AIDS Knowledge, Attitudes, and Beliefs Survey (KAB), administered in 1995, 1998, and 2000 by the Department of Health, suggests that Washingtonians overall have a "fairly positive attitude for general support and acceptance of people with HIV/AIDS."[3] The survey is fielded by telephone to a random sample of Washington residents age 18 and older. When respondents to the 2000 survey were asked, for example, if they would see a friend just as often if they learned the friend had HIV/AIDS, nearly 91% indicated they would. Five percent responded *No.* Differences in the response to this question between eastern and western Washington were small and not significant.

Despite these survey results, many prevention services providers within the AIDSNet regions report that stigma remains an obstacle to providing prevention services, particularly in some rural areas that are socially or politically conservative. People attach stigma to various aspects of the HIV/AIDS epidemic:

- Stigma about being infected with HIV or living with AIDS
- Stigma about the behaviors that result in HIV infection
- Stigma about groups of people who include those at more risk for HIV infection, including gay men, people of color, intravenous drug users, the mentally ill, the homeless.

Service providers report that stigma and fear remain significant barriers to their being able to identify people at-risk for HIV infection. Fear of being identified as having HIV infection – and being subject to the attendant stigma – also remains a significant barrier to people getting tested, regardless of their urban or rural location. Some within target populations fear, for example, that the local health department will publicly identify them as being infected with HIV or a person living with AIDS.

[3] Washington State Department of Health, Office of HIV/AIDS Prevention and Education. Washington State HIV/AIDS knowledge, attitudes, and beliefs surveys, 1995-2000, p.6; 2001.

The privacy and confidentiality elements of the AIDS Omnibus Act are contained in RCW 70.24:

- **70.24.105** Disclosure of HIV antibody test or testing or treatment of sexually transmitted diseases -- Exchange of medical information
- **70.24.450** Confidentiality -- Reports -- Unauthorized disclosures

These confidentiality mandates help to overcome stigma by ensuring that people who wish to, can remain unidentified within their community as having HIV or living with AIDS – they will not be identified through prevention services funded by the State. By continuing to support the privacy and confidentiality elements of the AIDS Omnibus Act, the Department of Health contributes to fighting stigma and creating an environment where people come forward to be tested.

FINDING: Public interest in HIV/AIDS has declined over time; other issues have taken priority.

The Washington State HIV/AIDS Knowledge, Attitudes, and Beliefs Survey suggests that in 2000, 91% of Washington adults felt that AIDS was a major U.S. health problem.1 Approximately 85% felt that they know either "some" or "a lot" about AIDS. Leaders in HIV/AIDS prevention services at the state and local level report, however, that they sense a decline in interest in HIV/AIDS within the general population and a decline in awareness of the continued epidemic, and devastating, nature of this infection. The events of September 11, 2001, and the succeeding anthrax contamination events have moved HIV/AIDS farther down the list of public concerns. These leaders suggest that public health messages about the realities of living with HIV would be useful for raising awareness about the epidemic.

Recommendation 15: The State should seek additional resources to broaden the HIV/AIDS prevention approach to encompass other blood-borne pathogens. In doing so highest priority for AIDS Omnibus Act funding should continue to be on HIV/AIDS prevention and education to high-risk populations.

FINDING: The work of the six AIDSNet Regions has become complicated by shifts in the epidemic and social needs not accounted for when the AIDS Omnibus Act was passed, including a rise in other blood-borne pathogens.

Many of the populations at risk for HIV infection also are at risk for infection from Hepatitis C virus (HCV) and Hepatitis B virus (HBV). HCV is one of the major causes of chronic liver disease in the U.S. and is spread by exposure to infected blood or contaminated drug injection equipment. Although data on HCV infection are not yet available in Washington State, the CDC estimates that as many as 100,000 Washingtonians might be infected with this virus. About one quarter of HIV-infected persons nationally also are infected with HCV, and co-infection is particularly common among HIV-infected intravenous drug users. HCV

infection progresses more rapidly to liver damage in persons with HIV, and can impact the course and management of HIV infection. Guidelines developed by the U.S. Public Health Service/Infectious Diseases Society of America recommend that all HIV-infected persons be screened for HCV infection.[4]

HBV is another cause of chronic liver disease and is spread by exposure to infected blood or bodily fluids and contaminated drug injection equipment. The CDC reports that in 1999, an estimated 80,000 persons in the U.S. were infected with HBV; data are not available for Washington. A vaccine is available for HBV.

Among key state and local participants in HIV/AIDS prevention there is a growing impression that efficiencies can be gained by combining other blood-borne pathogens with HIV testing, counseling, and other prevention services. Within some AIDSNet regions HIV prevention services providers report that they already are providing testing for HCV and vaccination for HBV, even though these services are not covered by HIV prevention funding.

Opportunities for combining prevention services for HIV/AIDS with services for HCV and HBV include:

- Combining prevention services for intravenous drug users, particularly through needle exchange programs.
- Incorporating information about strategies that reduce exposure to other blood-borne pathogens into education about HIV/AIDS harm reduction strategies, where appropriate.
- Improving disease investigation, partner notification, and peer recruitment of at-risk individuals.

Advocates for combining prevention services for HIV, HCV, and HBV (and possibly other blood-borne pathogens) stress that this should not be done using AIDS Omnibus Act funding. This funding already is stretched thin and has declined steadily (in real dollars) since 1991. Any expansion of services for other blood-borne pathogens should be funded with additional dollars targeted for that purpose.

Recommendation 16: The Department and the AIDSNet regions should continue to give priority to prevention interventions that are based on sound evidence or theory.

In the face of limited resources and increasing need for prevention services, HIV prevention services providers stress that the Department of Health and the AIDSNet regions should continue to give highest priority to HIV/AIDS prevention interventions that have demonstrated success for populations at risk for HIV infection.

[4] See www.cdc.gov/hiv/pubs/facts/HIV-HCV_Coinfection.htm

Recommendation 17: In considering recommendations for statutory or rule changes, the Secretary should ensure they:

- **Are scientifically sound.**
- **Decrease barriers to both providers and clients in the areas of testing and counseling, and diagnosis and care.**
- **Represent good public health practice.**

Any state statutory or rule changes that will affect the health of Washingtonians should be consistent with good public health practice. Changes regarding the planning of HIV/AIDS prevention services, targeting people to receive these services, and providing the services should be based on sound scientific evidence or theory. The recommendations developed by the HIV Prevention Study Committee support the Secretary, the Department, and HIV/AIDS planners and providers statewide in striving to decrease barriers to providers and clients in the areas of HIV/AIDS testing and counseling, and diagnosis and care.

Glossary

Acute Care: Health care in which the patient is treated for a brief but severe episode of illness; for conditions that are the result of disease or trauma; or during recovery from surgery.

AIDS: AIDS stands for acquired immunodeficiency syndrome, a disease in which the body's immune system breaks down. When the immune system fails, a person with AIDS can develop a variety of life-threatening illnesses. AIDS is caused by a virus called the human immunodeficiency virus, or HIV. A person infected with HIV receives a diagnosis of AIDS after developing one of the CDC-defined AIDS indicator illnesses. A person infected with HIV who has not had any serious illnesses also can receive an AIDS diagnosis on the basis of certain blood tests (CD4+ counts).

AIDSNets: The 1988 AIDS Omnibus Act (Chapter 70.24 RCW) establishes six AIDS service network regions encompassing Washington State. The AIDSNet regions were based on the State Department of Social and Health Services' six Community Services Administration (CSA) regions at that time.

At Risk: People are "at risk" for contracting HIV if they engage in certain activities that will expose them to the virus. HIV can be passed from person to person if someone with HIV infection has sex with or shares drug injection needles with another person. According to the Centers for Disease Control and Prevention (CDC), a person is "more likely to be infected" – that is, a person is at-risk for infection – with HIV if she or he:

- Has ever shared injection drug needles and syringes or "works."
- Has ever had sex without a condom with someone who had HIV.
- Has ever had a sexually transmitted disease, like Chlamydia or gonorrhea.
- Received a blood transfusion or a blood clotting factor between 1978 and 1985.
- Has ever had sex with someone who has done any of those things

The virus also can be passed from a mother to her baby when she is pregnant, when she delivers the baby, or if she breast-feeds her baby.

A person's risk for HIV infection can increase in the presence of other factors in her or his life, including biological (presence of STDs), economic (poverty), psychological (mental health stressors), behavioral (substance abuse), and social/situational (incarceration, racism, homophobia, sexism, lack of access to health care.)

CDC: The Centers for Disease Control and Prevention, within the U.S. Department of Health and Human Services.

Chronic Care: Health care in which a continuum of care is provided over a prolonged period of time for people who have lost, or never acquired, functional abilities. Chronic care

often is used interchangeably with long-term care in reference to nursing homes and home care agencies.

Co-Morbidity: The coexistence in an individual of two (or more) disorders; often refers to mental illness and substance abuse.

HIV: Human immunodeficiency virus (HIV) is the virus that causes AIDS; it is able to pass from one person to another through blood-to-blood and sexual contact and from mother to child at birth.

HRSA: The Health Resources and Services Administration, within the U.S. Department of Health and Human Services.

Incidence: The number of new cases of disease that occur within a given time period in a specified population at risk.

Pathogen: Any virus, microorganism, or other substance that causes disease; an infecting agent.

Prevention Services or Measures: Actions taken to reduce susceptibility or exposure to health problems, to detect and treat disease in early stages, or to alleviate the effects of disease and injury. Prevention interventions occur before the initial onset of disorder.

Prevention Case Management: Prevention Case Management (PCM) is a client-centered HIV prevention activity with the fundamental goal of promoting the adoption and maintenance of HIV risk-reduction behaviors by clients with multiple, complex problems and risk-reduction needs. PCM is intended for persons having or likely to have difficulty initiating or sustaining practices that reduce or prevent HIV acquisition, transmission, or re-infection.

Prevalence: The proportion of people in a fixed population with a specific disease at a given point in time.

Appendix A

HIV Prevention Study Committee

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Appendix B

HIV Prevention Study Committee AIDSNet Regional Meeting Summaries

HIV Study Committee Meeting Summary
AIDSNet Region 1
October 2, 2001

Region 1 AIDSNet Presentations

Overview of the Region's Structure and HIV/AIDS Epidemic

The Region 1 meeting began with a presentation by Dr. Kim Thorburn, health officer for Spokane Regional Health District, on the structure of Region 1 and the epidemiology of HIV/AIDS in the region. Although Region 1 comprises Spokane and 11 mostly rural counties, the region is becoming more urbanized. This creates tension over resource allocation between the more plentiful and easier to target urban cases, and the fewer and harder to find – and therefore at higher risk – rural cases.

Barry Hilt, the Region 1 AIDSNet coordinator, provided a brief overview of issues and challenges faced by Region 1, including underreporting of the disease by health care providers. Regions 1 and 2 also lost funds in the last revision of the AIDS Omnibus funds allocation scheme. Approximately 11 percent of the region's CDC and Omnibus funding goes toward administrative costs, including management and coordination of 18 prevention services contracts in 12 counties. The Regional Planning Group for Region 1 has 54 members.

Speaker Panel Presentations

A five-member panel of speakers from Region 1 presented their concerns and considerations regarding implementation of the AIDS Omnibus Act. The speakers represented Spokane County, Spokane AIDS Network, Blue Mountain Heart to Heart, Whitman County Health District, and a preventive services client. In preparing their remarks, the speakers were asked to respond to the following questions:

- What is working and not working in the current Regional Planning Group process?
- Are current prevention efforts responsive to the prioritized populations?
- What needs to be changed to make HIV prevention in your area more effective?
- What is being done to prevent behaviors that transmit HIV among the target populations?
- How is the regional AIDSNet structure working or not working, and what are barriers to success?
- Describe the unique care issues and challenges as you see them.

What's Working

The regional system has worked very well in this region, allowing for pooling resources and maximizing effective interventions. Several prevention programs are working well

specifically due to the regional system. The regional system is fair – when problems occur it usually is not due to problems inherent in the system, but rather in the system's participants (e.g., personality conflicts).

The regional system provides anonymity for rural cases, and program development and support for rural counties. The regional approach allows for small county issues to be aired and discussed. Small communities have a place at the table: this gives them an opportunity to network and learn from and share with others, especially with urban counties.

Community-based organizations (CBOs) and the Spokane Health District have a strong collaborative relationship. CBOs are critical to HIV/AIDS prevention in the region because they are able to combine efforts across programmatic boundaries.

Other Observations

One-on-one counseling and testing interventions work in rural areas, while group counseling and testing interventions do not.

What's Not Working

Much of what isn't working well in Region 1 centers on financial concerns:

- **Regional Funding.** The regional approach to funding is a problem for both Regions 1 and 2, which have experienced a continued gradual decline in funding due to the new Omnibus funds allocation scheme. This has caused local health departments/districts to become even more financially strapped.

- **Resource Allocation in Rural Areas.** Underreporting in rural areas leads to concerns about whether there is an adequate allocation of resources between the fewer and harder to find rural cases, as opposed to the easier to locate and more abundant urban cases.

Other concerns include:

- **Training.** Training for agency staff is not accessible and is underfunded. Training is focused on urban issues, not rural.

- **Regional Planning.** Frequent changes in the regional planning process can undermine both participation and creativity.

- **Administrative Burden.** Administrative requirements take a lot of time that is then not available to provide services. Policy changes also increase staff paperwork. Dealing with as many as three different funding cycles, depending on the source, adds to the administrative burden.

Other Observations

Providing AIDSNet services is difficult in regions where rural priorities do not mesh with the

urban center. Transportation, funding, information, anonymity, service array, availability of qualified staff, and poverty are all bigger challenges in rural areas.

Omnibus funds are being used for things that were not previously envisioned, such as mental health, homelessness, etc.

Participant Recommendations

- **Vested Interests.** The Regional Planning Group process could work better if individuals without a vested interest in obtaining funding were represented. If disinterested individuals could review funding decisions independently and make recommendations to the Regional Planning Group, this might expedite the process and make for a fairer, less biased distribution of dollars.

- **AIDSNet Coordinators.** A standard role should be established and clearly outlined for the regional AIDSNets coordinators.

Study Committee Discussion

Member Observations

The Region 1 meeting was the last in the series of HIV Study Committee meetings held in each AIDSNet region. Participating committee members offered their observations about what they had learned by visiting each region:

- Funding is insufficient, and the funding formula needs to be evaluated.
- More AIDSNet clients now have multiple diagnoses.
- Some target populations are hidden and inaccessible.
- The Ellensburg Agreement might have created problems in mandating that the AIDSNets work with the highest-risk populations.
- Needle exchange programs work; they have an impact on preventing disease.
- Regional meetings are useful and necessary for communication and collaboration.
- On-going care for people with AIDS is a bigger issue now than in 1988, when the AIDS Omnibus Act was passed.
- Regional planning takes a great deal of time, as do administrative requirements.
- Communication between systems, such as those for HIV care, mental health, and drug use, sometimes doesn't work.
- Political barriers create problems within some regions.
- CBOs are experiencing a decrease in volunteerism and private donations.
- Health education in the schools that covers all health messages is important.

Committee Questions

Committee members posed the following questions for future discussion:

- What are the pros and cons of changing the AIDS Omnibus Act?

- What can be changed in the current regional system? What could be kept? What could be removed?
- What is the minimum amount of infrastructure needed to run a regional system?
- Should the AIDS Omnibus Act cover STDs and HCV?
- Are local programs claiming Medicaid funds for care?

HIV Study Committee Meeting Summary
AIDSNet Region 2
October 1, 2001

Opening Presentation

State Focus Area: Counseling and Testing

This presentation specifically addressed two questions:

- Do counseling, testing, and referral (CTR) and partner counseling and referral services (PCRS) work?
- What does the Omnibus Law say about CTR and PCRS?

Evidence regarding the effectiveness of both CTR and PCRS is mixed. Some CDC studies demonstrate, for example, that "client-centered" counseling is effective in some populations, while other studies show an impact of such counseling in those who test positive for the HIV virus. The AIDS Omnibus Act requires that the AIDSNet regions provide both CTR and PCRS services, including anonymous testing. Counseling requirements – in the law and state rules – are applicable in both public and private settings. Counseling and testing services are almost all voluntary, but the law does provide for mandated testing in certain limited instances.

Between 1988 and 1992, the number of CTS tests administered annually in Washington State increased from approximately 15,000 to 50,000. The number of tests then remained fairly flat at about 43,000 between 1993 and 1996, and then declined to reach just under 30,000 in 2000. The proportion of positive results from CTS tests has gradually declined since 1988, from approximately 3.9% in that year to .9% in 2000. The proportion of positive results did increase slightly, however, between 1998 and 2000, the last year for which we have data.

Changes in CTR and PCRS since the AIDS epidemic began include:

- Purpose of testing
- Content of counseling
- How and to whom services are targeted
- Where services are provided
- Implementation of new testing technology

Region 2 AIDSNet Presentations

The discussion opened with comments from Dennis Klukan, Yakima Health District Administrator, and Jim Lewis, Yakima County Commissioner. They offered that the Washington State AIDS Omnibus Act and the regional AIDSNet system it established is a unique and

excellent system for addressing HIV/AIDS. Our state's system serves as a model for other states. But there is substantial concern that funding for the AIDSNets will be scaled back.

Two panels followed Klukan and Lewis, offering insights on how the AIDS Omnibus Act and the regional AIDSNet system is working for them, how it is not, what barriers exist to delivering effective HIV prevention services, and how care and prevention are linked. The first panel comprised several members of the community and community based organizations (CBOs), as well as some patient representatives. The second comprised four local public health representatives.

What's Working?

- **Regionalization.** Many things are working in the Region 2 AIDSNet. Primarily, the regional approach is a real strength, allowing for recognizing inherent cultural differences within different parts of the state. The AIDSNet planning and negotiations allow for equitable distribution of dollars, effective collaboration with regional partners, and the ability to respond to changes in the epidemic. The flexibility and community responsiveness of the AIDSNets are key features of their success. Having a regional approach means that if people work together workflow is more efficient and people's time is not wasted. The regional approach also allows for outreach efforts to expand beyond Yakima. Not only have the counties within Region 2 worked together well, but Regions 1 and 2 also have come together.

  Several panelists observed that the regional approach is so successful in large part because those involved in the AIDSNet are dedicated to the regional approach.

- **Community Partners.** Community volunteers and partners are critical to the success of the Region 2 AIDSNet. Ricardo Garcia of the KDNA radio network reports that he has formed strong partnerships with the community, and that the Washington State Department of Health (DOH) has been supportive of these relationships.

- **Public Health Providing Services.** The link between public health providers and HIV/AIDS preventive service provision is appropriate and effective because public health is seen as a neutral entity. This helps defuse certain charged issues related to the disease and those seeking services for it.

- **Other.** In contrast to Region 1, Region 2 has found that group sessions are a very successful approach (compared to individual contacts).

  Confidentiality is of critical importance in small rural communities.

What's Not Working?

- **Rural Issues.** Region 2 faces problems with transportation and access to care as a result of its rural nature. Some panelists feel these are "nearly insurmountable" barriers. Furthermore, interventions that are pilot tested and formulated for urban regions (and whose effectiveness is evaluated based on success in urban regions) are

not often effective in rural regions. Targets need to be adjusted based on rural needs (for example, men-who-have-sex-with-men is not as appropriate in rural areas as it is in urban areas). The flexibility needed to work in migrant camps is a special challenge in this region.

- **Funding.** Omnibus funding for Region 2 was reduced in 1995 when the new formula went into effect and currently, half of the regional state Omnibus funds in Yakima go to the needle exchange program and related activities. The Region 2 AIDSNet has experienced major grown in clients, but has even less staff now than when it was established. The region constantly feels it is trying to do more with less. The logistics of pooling resources (in eastern and central Washington) can be a challenge even though it increases efficiency.

- **Shift in the Epidemic.** HIV/AIDS is just being recognized in certain populations, including among Hispanic people and women (of any race or ethnicity). The region must do a better job of reaching such populations with prevention interventions.

Participant Recommendations

Recommendations offered by speakers include:

- Base Omnibus funding on HIV cases, not AIDS cases.
- The Board of Health rules addressing counseling and testing are dated and in need of revision, primarily because the options and services available to those infected with HIV have changed substantially since 1988.
- The STD control infrastructure and its linkage with HIV prevention must be strengthened, especially in communities where STD rates are climbing.
- The formal linkage between prevention and care should be strengthened. Once this is achieved, then prevention efforts can be formally integrated into case management.

Study Committee Discussion

Comments

- Committee members were concerned about the burden imposed by requiring the AIDSNet regions to do extensive outreach programs to populations they may not have in their region.

Questions

- Is there a minimum amount of money needed to keep the AIDSNets running?
- Does the needle exchange program in Yakima meet the AIDS Omnibus Act's prevention needs?
- Can we “roll up” the regional role in planning to the state level? What would be lost in doing this?

Conclusions

The committee observed that local priorities cannot be eliminated based on national priorities.

HIV Study Committee Meeting Summary
AIDSNet Region 3
September 24, 2001

Opening Presentation

State Focus Area: Are funding streams and levels for the AIDS Omnibus Act and other HIV/AIDS prevention funding responsive to the current epidemic?

Jack Jourden, Director of Infectious Disease and Reproductive Health with the Washington State Department of Health (DOH) offered an analysis of HIV/AIDS funding streams and levels in the state. Currently, funding is allocated by the Secretary of Health to the lead county in each AIDSNet region through contractual agreements based on each region's prevention plan. The regions are responsible for developing their prevention plan, and the plan must include any counties that do not participate in the planning process. DOH is responsible for ensuring that the planning process occurs at the regional level and that all regions participate. If an AIDSNet region decides not to develop a plan, DOH must develop one for it.

Services that must be addressed in the regional plans include:

- Voluntary and anonymous counseling and testing.
- Mandatory testing and/or counseling for certain individuals.
- Notification of sexual partners of an infected person.
- Education for the general public, health professionals, and high-risk persons.
- Interventions to reduce the incidence of HIV infection among high-risk groups.
- Outreach services for runaway youth.
- Case management.
- Strategies for developing volunteer networks and coordinating related agencies within the network.
- Other necessary information, including needs particular to the region.

Factors on which the current funding formula (developed in 1995) is based, and their weight in the formula, include:

- Total population (30%)
- Hepatitis B rate (2.5%)
- Results of a survey of childbearing women for HIV (2.5%)
- Teen pregnancy rate (2.5%)
- Estimated number of men who have sex with men (MSM) (15%)
- Increase in the proportion of reported AIDS cases (10%)
- Proportion of the population that is African American or Hispanic (5%)
- Proportion of the population that is rural (2.5%)
- Number of AIDS cases in MSM (15%)

- Number of AIDS cases that are intravenous drug users (IDUs) (15%).

A new formula is under development currently with only four weighting factors:

- Total population
- Proportion of the population that is people of color and at risk
- Total population living with HIV/AIDS
- Incidence of HIV in a region over a given period of time

Between 1989 and 2000, the allocation of funding shifted somewhat among the different regions. Notably, every region other than Region 4 has seen a decrease or no change in funding levels, whereas funding in Region 4 increased by about 5 percentage points. Region 4 also receives the highest proportion of Omnibus funds (41% in 2000).

The Ellensburg Agreement drafted in 1997 stipulates that all CDC funding must be targeted consistent with priorities identified in the region's community HIV prevention plan, and that the State Planning Group would set aside annually up to 10% of CDC funds for statewide prevention needs. The Agreement also stipulates that 50% of Omnibus funds in each region must target interventions aimed at priorities identified in its HIV prevention plan.

Fiscal accountability differs for AIDS Omnibus Act and CDC funds. CDC grants require a contract and substantial reporting, and are generally more "directed." Omnibus funds have fewer such requirements and are more flexible. DOH acts as a "pass-through" agent for Omnibus funding.

Region 3 AIDSNet Presentations

Overview of the Region's Structure and HIV/AIDS Epidemic

M. Ward Hinds, health officer for Snohomish Health District, reported that there are approximately 434 persons living with AIDS in Region 3, and another 213 who are HIV positive. But HIV/AIDS reporting does not accurately capture all of the cases. Overall, the epidemiology of the HIV/AIDS epidemic within Region 3 has mirrored trends statewide. The epidemic is becoming younger and more female. Region 3 has focused primarily on education and intervention strategies that are research-based.

Alexander P. Whitehouse, regional coordinator for Region 3, offered an overview of the region's structure and planning process and how both have evolved. He observed that the networks established with the AIDSNets regions are not static; rather, they are dynamic and constantly evolving within the general framework provided by the regional structure. They respond to changes in the epidemic, in the needs of the public and political leadership, and in the administration and focus of the regional plan.

What's Working?

- **Collaboration.** Collaboration between health educators and AIDSNet staff has been successful. Collaboration also is working well between the Snohomish Health District

(SHD) and the community. SHD has made a good name for itself within the community, and its staff members are easily accessible. Community participation in the regional planning process and service provision overall is excellent (including partnerships with Planned Parenthood, the PTA, etc.) and when community buy-in is sought, the exchanges are effective. There is a great deal of mutual support between programs and organizations within the AIDSNet, which allows the region to target some people they otherwise could not. Collaboration also has worked among case managers; between the public and private sectors; and across all participating organizations.

- **Regional Approach.** Working as a region has worked very well for Region 3 and participants are very invested in it. Participants in the region share information, develop programs together, and refer clients to each other's programs. All of this reduces administrative duplication. Being part of an AIDSNet region also gives participants access to more, good data.

- **Needle Exchange.** The needle exchange program in Region 3 allows for identifying people at highest risk in the community, and provides a good opportunity for education. The needle exchange program also represents outreach, or "going to where the people are," which is generally highly successful.

- **Other.** The Region 3 staff is good, qualified, passionate, and dedicated to its work. Population targeting is very effective (for example, incarcerated drug users or MSM). The planning process is working because it includes a diversity of participants and enjoys the strong support of the AIDSNet staff. Local input is effectively gathered through this process.

What's Not Working?

It can be difficult to identify communities to target in this rural region, with its dispersed population. In the relatively conservative, rural setting of Region 3 there is stigma associated with being HIV positive or having AIDS. The region also faces language barriers in outreach to the Hispanic population, as it has no bilingual or multilingual staff

The volunteer "lay" people on the regional planning council can find it overwhelming to go through the science involved in goal setting.

The region faces an overall lack of resources for drug treatment and behavior modification programs. The number of outreach staff is insufficient and in general, people with AIDS in Region 3 are very poor and therefore are more preoccupied with things other than their HIV status. Overall, the funding level for prevention services is not sufficient.

Study Committee Discussion

Member Observations

The Region 3 meeting was the third in the series of HIV Study Committee meetings held in

each AIDSNet region. Participating committee members offered their observations about what they had learned thus far:

- The committee has heard an overwhelming amount of information, which will require substantial analysis.
- The regional AIDSNet structure appears to be working well. The AIDS Omnibus Act appears to support the demographic and epidemiologic differences within regions.
- The flexible use of funding allowed by the AIDS Omnibus Act is a benefit that should be maintained.
- Other social problems, such as homelessness, mental illness, and drug use, create barriers to prevention, and they sometimes are not addressed.
- The committee may not be getting the information it needs to answer DOH's three mandated research components:
  - Review the goals of prevention strategies under the AIDS Omnibus Act in relation to trends in the current epidemic.
  - Analyze funding streams and levels for the AIDS Omnibus Act and other HIV/AIDS prevention funding.
  - Review the interaction and coordination of HIV/AIDS prevention programs with care services.

HIV Study Committee Meeting Summary
AIDSNet Region 4
September 17, 2001

Opening Presentation

State Focus Area: What service data collection systems do we have?

John Peppert, with the Washington State Department of Health (DOH), provided an overview of service data collection systems used by DOH and the regional AIDSNets. The primary database is the "Statewide HIV/AIDS Reporting and Evaluation System," or SHARE. SHARE collects information on the populations targeted and the interventions planned within each region, using the regions' intervention plans, and by the Department, itself. A variety of forms are used to collect this information. The Department is working with the University of Washington to develop standard outcome measures for assessing prevention services provided by the AIDSNets and the State. The CDC requires outcome evaluation for at least one intervention. And finally, the Department collects data on other markers that can suggest HIV/AIDS infection patterns, such as gonorrhea statistics.

State Focus Area: Creating a population and workforce knowledgeable about HIV/AIDS and preventing or reducing behaviors that transmit AIDS.

The AIDS Omnibus Act requires general education of many groups in the population (including employees, colleges, universities, vocational schools, and common schools). The content of such education must address sexual abstinence as well as avoiding substance abuse. Education also is required for "high-risk groups," as are intervention strategies that will reduce the incidence of AIDS within these groups. Overall, the education efforts have been very successful.

In general, for AIDS prevention education to work, the following things are necessary:

- Providing multiple exposure to a message
- Tailoring the message and making it relevant to the listener
- Integrating information with other knowledge
- Tying the message to other parts of the listener's life
- Providing information based in theory
- Delivering skills-building components and functional knowledge into the message

Region 4 AIDSNet Presentations

Overview of the Region's Structure and HIV/AIDS Epidemic

Karen Hartfield, AIDSNet Coordinator for Region 4, described the structure of Region 4 and the epidemiology of the epidemic in the region. Region 4 comprises King County, alone,

which has the largest share of AIDS cases in Washington at 65% (6,096 people). The number of newly reported AIDS cases is on a downward trend, but cases are increasing in rural areas. Overall, African Americans and Hispanics are most disproportionately impacted by AIDS in this region – that is, the number of AIDS cases is not representative of their share of the total population. Finally, the number of women with AIDS is increasing.

Hartfield observed that community-based organizations (CBOs) are the "cornerstone" of Region 4's efforts at HIV/AIDS prevention. A community review panel is responsible for reviewing applications from CBOs for funding and recommending funding levels to Public Health - Seattle King County (PHSKC). Programs that duplicate one another are not funded.

HIV Counseling and Testing in Region 4

Frank Chaffee, with PHSKC, provided an overview of counseling and testing services and concerns in Region 4. Counseling and testing are offered in both the private and public sectors. Although 80% of testing occurs in the private sector, most new HIV+ cases are identified through testing at public sector sites (higher risk individuals are triaged to these sites). Private sector testing sites include a physician's office, non-profit organizations, and home collection kits; public sites include public health clinics and community-based and social outreach sites.

Current trends in counseling and testing include a variety of new testing methods (such as rapid tests and home collection kits) and an increased use of outreach service models, "peer referral," and "motivational interviewing." The outreach service model, oral fluids collection testing, rapid test results. and alternative counseling methods have all been successful. Twenty-five percent of those tested prefer the rapid test to other alternatives. Barriers to testing include individual factors (e.g., fear), system factors (e.g., lack of anonymity), testing factors (e.g., anxiety) and counseling factors (e.g., dislike of counseling).

What's Working

- **Collaboration.** Organizations that have the capacity to offer more than one service to a client are very helpful. Organizations also are partnering together in an effort to provide multiple services to people with HIV/AIDS. This benefits the client. Referrals are very important and critical, and the use of collaborations has promoted this practice.

- **Needle Exchange.** The needle exchange program has been a very successful. The program allows for counseling intravenous drug users about drug use and HIV/AIDS at the same time. The program has allowed King County to reduce the spread of HIV much earlier among intravenous drug users.

- **Targeting Populations.** Targeting specific populations (such as intravenous drug users or men who have sex with men) has also been working well in Region 4. Mass media campaigns (attempts at overall education of the general population) have not been successful to date. More such campaigns are needed to get the messages across. Also, creating contextual messages about HIV is very effective.

- **Other Successes.** Connecting efforts at AIDS prevention with sexually transmitted disease (STD) prevention has been successful.

What Isn't Working

- A major problem in Region 4 is people with comorbidities (mental illness, drug abuse, homelessness, incarceration, etc). Very few services are provided to people with these other problems that contribute to HIV/AIDS. Substance abuse counselors, for example, are not trained to provide counseling on matters of HIV/AIDS. There needs to be a specific push to better integrate substance abuse services with HIV/AIDS prevention and education.

- A focus on the incarcerated population is not appropriate. Specifically, these populations are often housed in facilities that are located outside King County and Region 4. Therefore, continuing to provide services for them would involve crossing regional boundaries.

- The environment in which services are provided should be carefully thought out. Such environments must be appropriate to the targeted population.

- Certain target populations lack leaders and lack a unified message of prevention. Furthermore, often there is no "face" to the message because of a lack of "celebrity sponsors." This ties in with the problems around ineffective media campaigns in King County.

Participant Recommendations

Recommendations presented by public participants in the Region 4 meeting include:

- The four key themes to think about in reviewing the AIDS Omnibus Act are efficiency, accountability, privacy and confidentiality, and funding.

- The review committee should think about how to maximize the funding allocated now.

Study Committee Discussion

Committee Questions

Would you change anything that has to do with funding?

- Yes. Region 4's funding is not proportional to its share of HIV/AIDS cases (41% of state funding and 65% of statewide cases). The argument behind this was that Seattle is a large urban center that has access to more outside resources and sources of funding. But Seattle has a high cost of living and salaries for prevention workers have not kept pace (although they have in care services). This results in an insufficient supply of needed prevention services. Also, some of the affected population is moving

out of the county but still is getting services in King County.

Mass media campaigns have not proven successful [for some public health messages]. Are they successful for HIV/AIDS?

- Media campaigns are appropriate only for some target populations. The message must be specifically tailored to the appropriate form of media predominantly used by that target population.

HIV Study Committee Meeting Summary
AIDSNet Region 5
September 26, 2001

Opening Presentation

State Focus Area: Are the interactions and coordination of the HIV/AIDS prevention programs with care services responsive to the current epidemic?

Raleigh Watts and John Peppert, both with the Washington State Department of Health (DOH) provided an overview of interaction and coordination of HIV/AIDS prevention and care programs in the state.

Many different public programs at the federal and state level support care services, causing service delivery to become very complicated. Both expenses and the number of patients seeking preventive and clinical care have risen since 1995 – the former experiencing a 12-fold increase and the latter a 4-fold increase. This has stressed the entire system, especially existing resources. But regular, steady funding is essential to ensure people receive continuity of care. The AIDS Omnibus Act's focus was on providing a community-based continuum of care model with a goal of keeping a person with AIDS in a home-like setting until he/she dies. This is no longer representative of the majority of people living with AIDS or their preventive – or clinical – care needs. With medical advances people who are HIV+ and people who are living with AIDS are living longer, fuller, and more productive lives than their counterparts in 1988.

Region 5 AIDSNet Presentations

Overview of the Region's Structure and HIV/AIDS Epidemic

Presentations and testimony heard by the study committee in the region were offered separately for Pierce County and Kitsap County, the sole counties comprising the region.

Pierce County

The epidemic has changed in Pierce County: AIDS cases reported between 1984 and December 31, 2000, have included an increasing proportion of women, people of color, and cases due to injection drug use and heterosexual transmission. Pierce County has its own Prevention Planning Committee (as does Kitsap). The committee works directly with the Tacoma-Pierce County Health Department – the lead agency – and is responsible for planning services, prioritizing populations to serve, and approving the budget given to it by the Department.

The Department has taken a very traditional public health approach to disease control,

focusing primarily on identifying infected individuals and notifying their partners. The Department feels it has more rigorous standards for disease control than does the state, in this case including monitoring HIV+ people through a registry. (Although a later attempt was made to clarify that the registry "is not a list," it was not made clear exactly what the registry contains.)

The Department is investigating whether it can require HIV testing of the following groups of people:

- All pregnant women
- All incarcerated people
- All people who see their health care provider for another STD

Required testing is necessary because the Department is not reaching the people it needs to reach. They are being offered testing, but they are refusing – when in reality, they need to be tested. The Department's focus is primarily on disease control, but in a compassionate way. The Department would like to see the stigma removed from HIV/AIDS, that it just be seen as another STD.

Kitsap County

Kitsap County is unique in Washington State because Asians comprise the second largest population group after whites. As of September 2001, the county had 171 AIDS cases. A good proportion of people getting tested for their HIV status have been previously tested, raising concerns about gaps in prevention services that result in the need for retesting rather than in a reduction or elimination of risky behaviors. Many people in Kitsap County take the ferry to Seattle to receive their care services.

Kitsap County feels that its HIV/AIDS data (numbers) are so small compared with Pierce County that they get "swallowed" by the larger county's data.

Speaker Panel Presentations

What's Working in Pierce County

- The AIDSNet process works to a degree. Policy development provided by DOH works well, as certain things benefit more from the statewide approach.

- The Omnibus' community planning requirement ensures that communication takes place, because otherwise there would be none in this county.

- The Tacoma-Pierce County Health Department's Network Nurse Program, wherein a nurse goes to providers to advise them on the status of the HIV/AIDS epidemic, is working well.

What's Working in Kitsap County

- The two counties' separate and distinct HIV/AIDS planning processes is an arrangement that works very well for Kitsap County.

- Kitsap has established a program entitled " Syringe Access Kitsap," a syringe sales program that is working well.

- Collaboration with CBOs is critical and very effective in Kitsap. These collaborations are especially useful because they help compensate for limited resources.

- Kitsap adds a component of prevention to their case management services right away after an HIV+ diagnosis. This is an effective intervention in that immediately gets people services.

What's Not Working in Pierce County

- **Communication.** Communication between the Tacoma-Pierce County Health Department and community-based organizations (CBOs) and the community as a whole is lacking. This sentiment was strongly reflected by many of the panelists. One CBO representative asserted that, as an example of this, she had not known until this meeting that there was an HIV+ registry. The disconnect particularly extends to communities of color, who are not accessing services. Furthermore, representatives of the Prevention Planning Committee asserted that the budget given to the committee by the Department never reflects the plan the committee developed. The Department shows the committee the budget, but does not accept feedback on it. Often, duplication of CBO services exist in the budget, and panelists wondered whether this is political. The high turnover rate at the Department has created problems with regard to continuity of relationships and interactions. The CBOs feel they are in "defensive mode" with the health department and that this inhibits their ability to produce good, pro-active, communicative planning. In addition, the CBOs do not know each other well, and there is not enough communication among them.

- **Funding.** Funding for prevention services is insufficient. Panelists asked why AIDS Omnibus Act funds are diverted by the health department for administration when HIV/AIDS care has plenty of funding but prevention does not. The funding from the AIDS Omnibus Act has been flat, not keeping pace with inflation. The need for funding in prevention is great; most private fund-raising goes to prevention.

- **Other.** Some panelists felt that the AIDSNet region is redundant and not necessary in Region 5. The accessibility of the AIDSNet coordinator, and his or her ability to consider new ideas, varies greatly depending on the person in the position.

What's Not Working in Kitsap County

- **Structure.** Pierce and Kitsap counties need to be separated because of their very different characteristics. Kitsap should be joined with Clallam, Jefferson, and Mason

counties instead because these counties are far more similar and together, could comprise a new AIDSNet region. The Narrows Bridge is a barrier that stops Region 5 from working effectively.

- **Funding.** Kitsap lacks funding for care services, and its case load for these services is growing. Pierce County has Ryan White Title III and Title IV care funding, as well as significant private funding for care services. Kitsap County also has insufficient funds for providing necessary prevention services. The county is changing its priorities, especially with how case management time is used.

- **Rural Access.** Finding at-risk populations is difficult, as they are dispersed in this county. Targeting migrant workers for prevention services also is difficult. Transportation is a barrier to receiving services. Other barriers to receiving services include: stigma, fear of the police, and fear of the local health department.

Study Committee Discussion

Questions

Should we leap to the conclusion that the AIDS Omnibus Act is antiquated because it did not deal with care services? Would there be any utility in trying to get some balance between prevention and care in the legislation?

Should the Act focus on targeted education instead of generalized education?

What is the role of the military institutions in the two counties in this AIDSNet region?

- In Pierce County, the military has been very cooperative with the health department's partner notification. Someone from Fort Lewis was once on the Prevention Planning Committee, and a local CBO has provided anonymous testing to active military personnel.
- In Kitsap County, there are a number of active military personnel and survivors of deceased active military in the County's case management program. The Bremerton and Bangor military bases often respond to overtures from the County with "We don't have a problem here. We have our own HIV/AIDS training."

Should Region 5 be split into two regions?

HIV Study Committee Meeting Summary
AIDSNet Region 6
September 10, 2001

Opening Presentations

State Focus Area: Are the goals of the prevention strategies under the AIDS Omnibus Act responsive to the current epidemic?

To answer this question, the Region 6 meeting began with a presentation by Nancy Hall with the Washington State Department of Health (DOH) that addressed how community level participation in decision making, program development, and program implementation is encouraged. She described the evolution of the AIDSNets and the role that community participation plays in their success. The AIDS Omnibus Act was passed in 1988, establishing six regional networks and requiring that an annual service plan be developed for each region to reflect the characteristics of the region's HIV/AIDS epidemic. Funding for the AIDSNets in 2000 was $8,134,663 through the AIDS Omnibus Act and $3,908,050 from the CDC. The presentation concluded with the following three principles of HIV prevention community planning:

- Community voices are essential.
- HIV prevention dollars must lead the epidemic.
- All interventions must be based on sound science and public health practices.

Region 6 AIDSNet Presentations

Overview of the Region's Structure and HIV/AIDS Epidemic

Karen Steingart, Medical Director for AIDSNet Region 6, gave an overview of the structure of Region 6 and the epidemiology of HIV/AIDS in the region. Importantly, Region 6 is comprised of eleven counties spanning an area from the Oregon border to the Olympic peninsula, with a total population of one million people. A full one-third of this population is located in Clark county, which is just outside of Portland, Oregon. The majority of people infected with HIV/ AIDS in Clark County receive their care in Portland. Region 6 has a low population of people of color and several counties have very serious drug problems (e.g., Thurston, Cowlitz, Pacific).

Region 6 has needle exchange programs in five of its 11 counties (Clark, Thurston, Cowlitz, Clallam, and Jefferson). The remaining counties do not have such programs because although AIDSNet regions cross jurisdictional boundaries, only local boards of health can decide whether to fund needle exchange programs. Federal funds cannot be used for needle exchange.

Prevention Planning Committee Presentations

The Region 6 HIV Prevention Planning Committee is specifically targeting people within three risk transmission categories: intravenous drug users (IDUs), men who have sex with men (MSM), and high risk heterosexuals. The committee altered the State Planning Group's weighting scheme for identifying target populations to better reflect the epidemic in its region. Key barriers to prevention efforts include stigma and the social and political environment of local areas. People with HIV/AIDS also are living longer through the use of medications, increasing the need for prevention education. Region 6 uses funding streams in various ways to maximize both dollars and prevention efforts specific to the nature of the epidemic. The unique situation of Clark County being within Portland's Ryan White CARE Act (Title I, 1990; 1996) eligible metropolitan area (EMA) is at times problematic for the planning group, primarily because the priorities of the Portland EMA are often different from those of Region 6 and of Washington State.

What's Working, What' Not

Region 6 has found that the AIDSNet structure is useful for planning appropriate prevention services and facilitating dissemination of funds. The region also finds that having a strong, regional policy board to set guidelines and provide oversight is invaluable. The community involvement required in the AIDSNet planning process is generally working, resulting in better compliance and interventions, and more appropriate interventions for diverse groups. Barriers to community participation include cost, time, effort, the small effect in terms of number of people targeted, and the time lag between planning and implementation.

As in all of the AIDSNet regions, demand for services has increased in Region 6 while funding has decreased. Guidance from the Region 6 Prevention Planning Committee regarding focusing resources on priority populations and effective interventions has worked well for local health departments within the region (specifically Gray's Harbor), as this approach targets limited resources and maximizes effectiveness. People involved in planning and implementing the region's prevention efforts have found that making reference to these regional priorities can be productive when discussing controversial interventions with policymakers and constituents.

For those involved in the region's HIV/AIDS prevention efforts, problems include coordinating their efforts with other services (such as vocational rehabilitation, mental health, and housing services) and inconsistencies and incompatibilities with some service planning processes. In particular, Clark County being within the Portland EMA has created planning and implementation difficulties for the whole of Region 6. These include:

- The Portland EMA and Washington's Region 6 AIDSNet have two separate planning processes.
- The Portland EMA's priorities often are not the same as those for the Southwest Washington Health District or for the Region 6 AIDSNet.
- Community-based organizations in Clark County have to meet the requirements of both the Portland EMA and the Region 6 AIDSNet.

- Many of the Portland EMA's care and affiliated programs are provided in Portland, and access to the city can be difficult for Clark county residents.
- Because some of the Southwest Washington Health District's funding comes from the Portland EMA, sorting out funding streams and their related services between the EMA and the Region 6 AIDSNet is difficult.

The physical size and diversity of Region 6 can present challenges in delivering prevention services. This diversity sometimes translates into a disconnect between regional planning efforts – including identifying target populations – and local community-level implementation. The care-prevention connection can be difficult in some local communities, particularly in Clark County where the split funding poses a challenge to integrating prevention services with case management. Finally, the characteristics of people with HIV/AIDS are changing in this region: there are more who have the disease that are homeless, mentally ill, or poor. Generally, people with HIV/AIDS have more severe issues now than when the AIDS Omnibus Act was passed.

Participant Recommendations

Recommendations presented by members of the Region 6 Prevention Planning Committee include:

- Areas that are small and rural in nature benefit from being within the same AIDSNet region as large urban areas that have more technical expertise and assistance. If the regional structure changed in some way, such expertise might be cultivated at, and offered by, DOH.

- Current funding does not, but should, account for the cost of building political will within a community.

Study Committee Discussion

Committee Questions

Should the AIDS Omnibus Act look broader than just at HIV/AIDS and include other blood-borne diseases, such as HCV?

- Yes. Some HIV prevention service providers already provide the HBV vaccine to their clients, even though this activity isn't funded.